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ABSTRACT

This document comprises the nine issues of the 1999-2000 TASH Newsletter. Each issue includes news items, conference information, and articles. Major articles include the following: "1998 TASH Annual Conference: Inclusion Roundtable"; "1998 TASH Conference Keynote Address (Zuhy Sayeed); "Do Not Resuscitate - Whose Choice Is It?" (Nancy Noble); "The Utter Vulnerability of Persons with Mental Disabilities in Police Interrogation Rooms" (Robert Perske); "Closing Brandon Training School: A Vermont Story" (Bonnie Shoultz and others); "Pulling the Plug on the ADA?" (Jonathan D. Ezekiel); "A 'New' Dr. Death at Princeton" (Mary Jane Owen); "The Importance of Arts Education for All Students" (Florence Aversa); "The Promise and Pitfalls of the Workforce Investment Act" (Michael Callahan); "National Efforts To Promote Conversion: Day Programs to Supported Employment"; "Empowering Communication Aid Users" (Rosemary Crossley); "Inclusion Is Happening ...WHERE?" (Rich Villa); "International Human Rights Abuses against People with Mental Disabilities" (Eric Rosenthal); "What Is Culturally Appropriate? Finding a Middle Way" (Alexandra Enders); "Reflections about Positive Behavioral Supports" (Jacki Anderson); "Effective School Practice in Educating Students with Challenging Behavior" (Tim Knoster and Don Kincaid); "The Professionalization of Teaching and Learning for Children with Severe Disabilities: The Creation of TASH" (Ed Sontag); and "An Introduction to Disability Studies" (Perri Harris and Lori Lewin). (Some articles contain references.) (DB)

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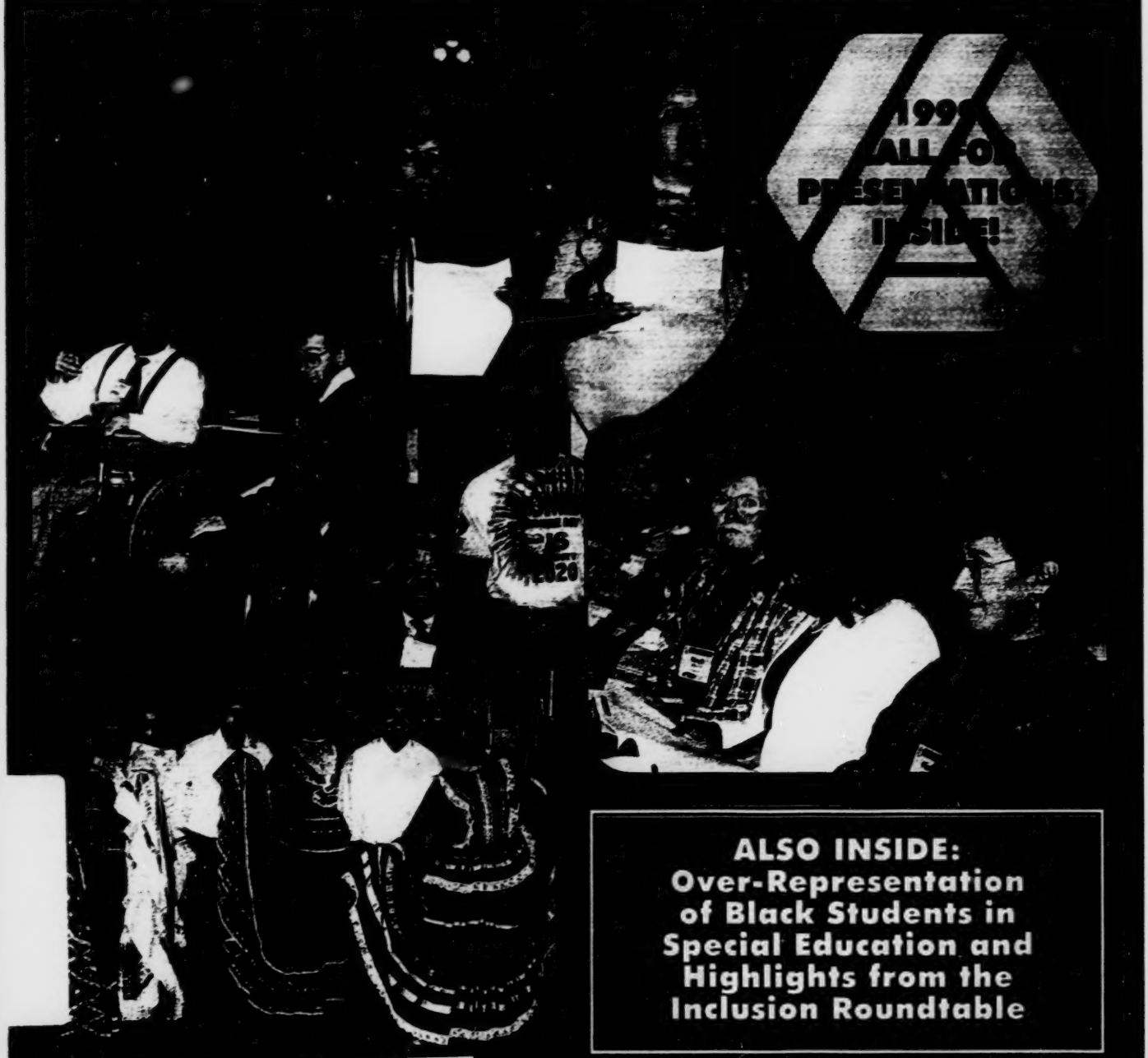
TASH Newsletter

VOLUME 25 ISSUE NUMBER 1/2 January/February 1999



ALSO INSIDE:
Over-Representation of Black Students in Special Education and Highlights from the Inclusion Roundtable

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1999 Calendar of TASH Chapter and Member-Sponsored Conferences

APRIL

Stories of Change: Annual CAL-TASH Statewide Conference
April 22-24
San Diego Marriott-La Jolla, CA
Contact: Eileen Medina,
Phone: 805-967-2042
E-mail: cal-tash@ceo.sbceo.k12.ca.us

The Sun-Tash/Arc Conference
April 22-23
Albuquerque Hilton
Contact: Liz Keefe,
Phone: 505-277-0987
Email - lkeefe@unm.edu

MAY

Education in Italy: An Inclusive Approach
May 18-June 9
Site visits to schools in Rome, Florence, Parma and other locations
Contact: Dr. Carol Berrigan, Seminar Director, Syracuse University
Phone: 315-443-3851
Email: crberrig@syr.edu

JULY

CAL-TASH Summer Symposiums in Santa Barbara
July 26-27 - "School Inclusion"
July 29-30 – "Positive Behavior Support"
Contact: Eileen Medina,
Phone: 805-967-2042
E-mail: cal-tash@ceo.sbceo.k12.ca.us

1999 Toronto Summer Institute
July 3-9
Toronto, Canada
Contact: Inclusion Press
Phone: 416-658-5363
Email: 74640.112@compuserve.com

SEPTEMBER

National Spinal Cord Injury Association
Annual Meeting and Education Conference
September 26-29
Washington, D.C. Marriott - Metro Center
Contact: Denise Marshall
Phone: 410-828-8274, ext. 103
Email: dmarsh@tash.org

DECEMBER

Annual TASH International Conference
"TASH 2000 – Our Turn Now"
December 8-11
Chicago Hilton and Towers
Contact: Kelly Nelson
Phone: 410-828-8274 x105
or 1-800-482-8274 x105
E-mail: knelson@tash.org

Do you have an upcoming TASH chapter meeting or member-sponsored conference that you would like to announce in the *Newsletter*? Send notice of the conference to Denise Marshall at dmarsh@tash.org at least 6 weeks before the event date. We will make every effort to include the event in the meeting calendar.

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible

~

Building communities in which no one is segregated and everyone belongs;

~

Forging new alliances that embrace diversity;

~

Advocating for opportunities and rights;

~

Eradicating injustices and inequities;

~

Supporting research and disseminating knowledge and information;

~

Promoting inclusive education;

~

Supporting progressive legislation and litigation; and,

~

Promoting excellence in services.

Self-Determination Synthesis Project

The University of North Carolina at Charlotte, through a grant from the US Department of Education Office of Special Education Programs (OSEP), is conducting a review and synthesis of the knowledge base and best practices related to self-determination (SD) for students. The purpose of the project is to improve, expand, and accelerate the use of this knowledge by the professionals who serve children and youth with disabilities, parents who rear, educate, and support their children with disabilities, and students with disabilities.

The synthesis component of the project will be accomplished through a review and meta-analysis of existing SD literature and a series of case studies of four exemplary sites that are successfully implementing SD interventions.

- The Project Team is currently seeking nominations for exemplary sites. These sites are schools/school districts that are implementing practices intended to enhance students' self-determination. **TO NOMINATE A SITE**, contact the Project Coordinator or visit our web site at *www.uncc.edu/sdsp*
- The Project Team is seeking literature and other materials related to SD research and practices. Examples may include published or unpublished manuscripts, project reports or evaluations, examples of curricula, or other materials.

The Self-Determination Synthesis Project is co-directed by Wendy Wood and David Test, with Diane Browder and Bob Algozzine serving as Research Associates. A Project Advisory Team, consisting of consumer/self-advocates, school staff, advocacy organization staff, parents, and researchers has been convened to help guide the project and ensure that the outcomes are appropriate for all consumer groups.

For more information about the Self-Determination Synthesis Project, or to nominate an exemplary site or piece of literature, please contact:

Meagan Karvonen, Project Coordinator
Self-Determination Synthesis Project
Special Education Program
University of North Carolina at Charlotte
9201 University City Blvd.
Charlotte NC 28223-0001. Phone 704/547-3736
E-mail: mrkarvon@email.uncc.edu

Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail dmarsh@tash.org
- **For questions about the 1999 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail knelson@tash.org
- **For questions about membership, conference registration or exhibiting call:** Rose Holsey, Director of Operations, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on government affairs or fundraising/development, call:** Marcie Roth, Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:mroth@tash.org
- **For information on marketing and promotions, permission and reprints, newsletter submissions and advertising, or publication sales, call:** Priscilla Newton, Director of Marketing and Communications, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the Journal (JASH), call:** Linda Bambara, Editor-in-Chief, at (610) 758-3271, e-mail: LMB1@lehigh.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette for people whose disabilities make this form preferable. Call (410) 828-8274 ext. 102 to request the recorded version. Requests for permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org

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From the Executive Director
BY NANCY WEISS

As Barbara Buswell, a former TASH Board member once said, "TASH is much more than an exciting yearly conference. It's more than the *Journal* that has articles that have helped us many times to get the things my family wants. It's more than the *Newsletter*, the committees, the Executive Board, the staff, the important resolutions, the governmental affairs presence and the other things that we do. TASH is a values-driven bank of individuals who actively live out a shared mission and make a difference in people's lives, day-to-day."

As it does each year, TASH's Executive Board held its annual meeting this year in conjunction with the national conference. Over its two days of meetings in Seattle, the Board undertook a structured strategic planning process to adopt a work agenda for the coming year. Committees participated in this process by reporting to the Board the issues they felt should be included in TASH's 1999 agenda. The purpose of this article is to update the membership about the priorities that were set as a result of the strategic planning process and to invite your input and participation as action plans are developed and implemented. We invite all members to affirm Barb Buswell's description of TASH by participating in designing and carrying out TASH's 1999 Strategic Plan.

The Board identified five priorities relating to advocacy and five relating to the operation of the organization. The priorities are listed below. Next to each priority I have noted the name of the Executive Committee member who is taking the lead in developing an action plan related to that priority. Contact information is provided for each of the Executive Committee members. The Board welcomes your input in the development and implementation of action plans for each of the identified priorities.

TASH's 1999 Action Priorities

Top Five Advocacy-Related Priorities:

		Lead Board Member
1.	Assure that IDEA is implemented and enforced	Donna Gilles
2.	Assure the right to communication for all people with disabilities	Doug Biklen
3.	Support the passage of MiCASA	Joe Wykowski
4.	Strengthen TASH's collaboration with general educators	Liz Healey
5.	Work toward justice for people with disabilities involved in the criminal system	Liz Obermayer

Top Five Operations-Related Priorities:

1.	Improve our web site and electronic communication	Doug Biklen
2.	Synthesize resolutions and develop new resolutions	Liz Healey
3.	Strengthen/Support chapters	Donna Gilles
4.	Develop a handbook for students on IDEA and self-advocacy	Liz Obermayer
5.	Fiscal development	Joe Wykowski

Contact information for the five members of the Executive Committee is provided below. If you have interest in any of the specific topics listed, please do not hesitate to contact the Board member assigned to that priority.

Liz Healey (President)
Phone: 412-995-5000, ext. 493
Fax: 412-995-5001
e-mail: healey@pps.pgh.pa.us

Doug Biklen (Vice President)
Phone: 315-443-2699
Fax: 315-443-2274
e-mail: dpbiklen@syr.edu

Liz Obermayer (Secretary)
Phone: 781-894-3600, ext. 2055
Fax: 781-398-0305
e-mail: liz.obermayer@dmr.state.ma.us

Joe Wykowski (Treasurer)
Phone: 503-292-4964
Fax: 503-292-6485
e-mail: 74452.3365@compuserve.com

Donna Gilles
(Chair, Executive Committee)
Phone: 352-846-2760
Fax: 352-846-0941
e-mail: gilles@ufbi.ufl.edu

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Committee Plans and Progress

TASH has over twenty-five committees that meet at the conference, and in some cases throughout the year, to pursue special areas of interest. Many of the committees met in Seattle to outline plans for the coming year. Highlights are as follows:

Chapter Operating Committee:

The Chapter Operating Committee held their Chapter Leadership Day on the Wednesday preceding the conference. The day was an unprecedented success with 31 chapter leaders, representing thirteen chapters, attending. Goals for the coming year include:

- Develop a chapter handbook.
- Survey chapters to determine the content of regular reports from central office.
- Plan the 1999 Chapter Leadership Development Day around presentations by different chapters.
- Coordinate efforts with the Membership Committee.
- Provide support to struggling chapters.

Community Living:

Action items for 1999 include:

- Assist with development of a book on community living.
- Work with Media Committee to disseminate stories about people with disabilities as contributing citizens.
- Support MiCASA.
- Look for ways to sponsor broad research concerning the health/safety and accountability of people in individual support systems versus larger settings.

Early Childhood:

Plans for this year include:

- Develop a new resolution on Early Childhood.
- Establish linkages with other organizations.
- Re-submit grant proposal to develop a comprehensive resource and information guide for families of young children with significant disabilities.
- Plan a crackerbarrel or strand for next year's conference.
- Work with JASH editorial staff to plan a topical issue.

Governmental Affairs:

The Governmental Affairs Operating Committee recommended focus on the following three priority areas:

- IDEA Implementation and Enforcement
- Passage of MiCASA
- Passage of a Work Incentives bill

Other issues the committee recommended that require TASH's attention include:

- Lead the effort to elect disability-friendly political representatives at every level.
- Support legislative efforts to close institutions and oppose the use of funds for institutions.
- Housing
- Legislation to promote positive approaches and prohibit the use of aversive procedures

Leisure and Recreation Committee:

This year's activities will include:

- Continue to represent TASH on the Outdoor Regulatory Negotiation Committee of the U.S. Access Board.
- Report results of this process in the TASH *Newsletter*.
- Establish a data base of TASH members to form a Leisure and Recreation Network for information sharing.
- Collect and disseminate best practice stories on inclusive recreation experiences.

Membership Operating Committee:

This year's plans include:

- Focus on both maintaining current members and recruiting new members.
- Work toward better communication between the Chapter Operating Committee and the Membership Committee.
- Study additional member benefits that could be offered.

Multicultural Committee:

Goals for this year are as follows:

- Send a letter to President Clinton urging the United States to rejoin UNESCO.
- Continue to include a strand on multicultural issues at the 1999 conference.
- Provide opportunities for discussion of international issues.
- Create partnerships with TASH's international counterparts.
- Review/revise relevant resolutions.

Paraeducator Committee:

This committee's goals are as follows:

- Create incentives for paraeduacators to become involved in TASH and in the conference.
- Examine standards for paraeducators to ensure that they uphold integrity for individuals with disabilities. Recommend & advocate change where standards do not accomplish this goal.

Personnel Preparation:

The committee discussed a variety of topics of interest and broke into sub-groups to develop action plans for each of these prioritized areas. Topics discussed include:

- Unified programs: do they address ALL students?
- Content/competencies for specialists
- Changing roles of special educators
- Changes in philosophy of best practices not reflected in current teacher preparation programs
- Opportunities for students with disabilities to attend college
- IHE need to model recommended practice
- Restructuring process
- IHE faculty need for continued professional development
- National data base of programs in severe disabilities
- Voice for all concerns

Positive Approaches Committee:

Goals for this year include:

- Revise the TASH resolutions relevant to positive behavioral approaches.
- Interface with the new committee on the legislative and policy aspects of positive approaches.
- Disseminate success stories and research which validate positive approaches.
- Create resource listings.

All committees welcome additional energy and interest. TASH members are invited to participate in committee activities. For information about contacting the chairs of any of these committees, call the TASH central office at 410-828-8274, or e-mail info@tash.org.

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1998 TASH Annual Conference:
INCLUSION ROUNDTABLE

We are pleased to present excerpts of the proceedings from the 1998 Inclusion Roundtable, a lively discussion facilitated by Dorothy Lipsky and Alan Gartner from the National Center on Educational Restructuring and Inclusion, located at The Graduate Center in New York. Panelists included: Rich Villa, Consultant; Phil Ferguson, National Institute for Urban School Improvement at the University of Oregon; Mara Sapon-Shevin, School of Education, Syracuse University; Charlene Comstock-Galagan, an advocate from the Arc of Texas; and Jacque Thousand, College of Education, California State University–San Marcos and TASH Board Member.

The audience was a balanced mix of parents (some who have children who are included and some who want inclusion but have not been able to convince the school system to cooperate); consultants; principals (of both fully included and segregated-moving-to inclusive schools); doctoral candidates; faculty members; special education coordinators; educational psychologists; statewide technical assistance coordinators; and special education and regular education teachers.

*l-r: **Alan Gartner, Inclusion Roundtable facilitator; Rich Villa, one of the panelists; and Dorothy Lipsky, co-facilitator of the Roundtable***

Dorothy Lipsky

It is really true – the power of what this assembled group of people know about how to solve problems. That is critical. This isn't really rocket science; it is just good problem solving skills and having a group of people that can collaborate and use their collective energy to really keep going forward.

Let me just tell you my own personal story for a moment. Parents sometimes wonder if it is still the right thing to have their children in inclusive classes. I want to help you remember in terms of all of the research and all of the personal stories that parents share with each other that the outcomes for youngsters in those general education classrooms, when we put the supplemental supports in there, is very powerful.

Partially the reason we wanted to make that shift was that we knew that the outcomes in the self-contained [classes] meant that they were not graduating from high schools. [Individuals] were still living at home to a large degree, and they were not getting adequate employment skills.

But now we have done the research, federal officials have done the research, everybody has done the research enough to know that it hasn't worked. We made some mistakes. It doesn't mean we are blaming the special education teachers or administrators, because they have had self-contained classrooms. That is what the law said to do.

Danny, my son, was born 29 years ago with Spina Bifida, a pretty severe birth defect at that time. I ran for the county school board and I won. When Danny was the first child with disabilities in the public schools, parents asked: "Was that part of the reason?" Well, it surely didn't hurt. **We do have to remember that we are the best advocates for our own children.**

Danny continued to surprise everyone and the teachers were very frightened by having him in a regular education class in a wheelchair. It gave them lots of problems and lots of cause for reflection. The best news that I have to tell you is that while I often thought of the Henry Viscardi School perhaps being the place for Danny — they had a lot of children with Spina Bifida there — the fact of the matter is that we as parents question sometimes "Are we doing the right thing by placing them in that situation?"

I believe very strongly that for Danny it was absolutely the right choice and he believes that, too. He ended up getting a high school diploma in New York, going to a regular education program throughout. It was very difficult. He had to have quality teachers who constantly had to think about how to present information to a different kind of learner. Even though I told you he got a high school diploma, he actually can only read at a third grade reading level.

Now, how did those high school teachers [accommodate Danny's learning style]? They thought of alternate ways of presenting the material because he could understand the material even though he could not read it. He couldn't write. They had to send note takers into class. They had to figure out how to put material on tape, get extra kinds of videos and books, cooperative teaching, having kids work together, whatever it took. Thank goodness technology came in at that time and helped Danny get that high school diploma.

After Danny was in a self-contained kind of employment situation (that did not work), he went to a college in Boston called Lesley College. They are very interested in working with children who have learning disabilities. They also train teachers in a very wonderful program. Danny went there. He was the first child with physical disabilities. He flunked out. He flunked out because what we had learned in high school we did not transmit to the college.

In some ways maybe we thought he was really going to be able to do this without all of the supports and without our still needing to be involved. You now how it is, you think he is grown up, graduated from high school and you ask yourself, how can I keep mothering to that level? But the fact is he needed some supports — the same kind of supports he needed in high school. He begged them to take him back the second year and they did. With the supports built in he was successful.

Danny met a girl there, Heather, who also had learning disabilities. They fell in love. I got a phone call and he says:

Continued on page 7

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INCLUSION ROUNDTABLE

Continued from page 6

"Mother at the end of the year I am not going back. Heather is finishing the program and we are going to Atlanta, Georgia to live."

In fact, Danny has lived in Atlanta with Heather for the past 4 years. He works in the college in a security office there with a vocational rehab counselor to do job coaching. She really helped Danny to do his job. Heather also has a job in a large company doing wonderful work. These kids have a wonderful quality of life – I cannot tell you the stories and the things that they have told us about how happy they are living there.

That's my parent side. The other part of the work that I do is the professional side. It is really looking at school districts that have been restructuring and are trying to take the concepts of inclusion and to go further. We have done research in about 1,000 school districts and we have asked the teachers and the administrators and the parents and the students themselves how they did it. We have lots of information which I will share with you. Now let me turn it over to our colleagues here to give a couple of words or thoughts about where they are in terms of thinking about the new federal regulations, IDEA. How the law is going to make a difference for the diverse groups that are here so that it can help them move forward in a strategic way.

Rich Villa

I had the good fortune of living in the State of Vermont for many years – the state that leads the United States in the inclusion of children with disabilities. I was the administrator in the school district that was probably one of the first totally inclusive school districts in the United States. Since that time for about the last four years or so I have had the opportunity to travel and work with a variety of people on their journey, their evolution toward this thing called inclusion.

Without a doubt I am convinced that **the number one determinant of whether a child is included is quite simply the place that you happen to live at the time and the disposition of the educators in that community**. I am encouraged by the changes in IDEA Reauthorization. However, we have had laws since 1975. If we had been implementing the previous versions, a lot of what you have described as obstacles and barriers would not necessarily be in place.

The things that I am excited about in IDEA Reauthorization would certainly be:

1. Access to the general education curriculum for children with disabilities.
2. Inclusion in assessment is just an absolute critical thing because so much assessment has been done and disregarded to this population of students.
3. The fact that there is a place where it says — for the first time – that students themselves, whenever possible, should be included in meetings.

With all due respect there comes a time when you are not going to be your child's best advocate. **We have to empower children and youth to become self-advocates and get them involved in the process early on**. Just as parents can come with advocates, kids should be able to come with advocates or lawyers in training.

We have kids come to meetings as young as kindergarten and first grade. Now you may not want to have them come to the whole meeting and you may want to have some opportunity to be flexible.

Question: *Are there any things that you have noticed in your work with school districts that have been particularly valuable in terms of what a school system really needs to think about for good inclusion?*

Rich Villa

I think I see inclusion occurring on a couple of levels. I see inclusion occurring for individual children. You do not have a system that is ready for those children. You have pushed, you have pleaded, you have evolved a relationship so that somehow the child shows up in a classroom. I see in that scenario a classroom teacher that is scared and frightened and I see a parent who ends up being the mentor to the classroom teacher, teaching the classroom teacher how to do accommodations and modifications. Sound familiar to anyone of you? Unpaid mentor. Pro gratis employees. And don't you have [an outside] job because then you are obviously not interested in your child's progress. Just when that teacher has got it- your child is ready to move on to the next grade. There has been no systematic initiative, no transition planning and you are right back to the beginning.

I see a lot of parents with a lot of energy in the primary grades. If that system does not change by the time the child hits middle school or high school, the complexity of those systems with the numbers of teachers they have, [the parents] are pretty worn out. On the other hand, I have seen school districts that continue to evolve and move to the place where there is more of a systematic response.

For me inclusion works in a place where:

- People are busy articulating the vision of what inclusion is and what it is not.
- People have redefined the roles. People are actively figuring out what to do differently. Everybody's roles, rules and relationships change.
- People are doing other kinds of school reform and restructuring. We need to clarify for people that our goals are the same for all children. General ed school reform initiatives such as multiage grouping, whether you are doing that or block structuring or constructivist approach to learning and multiple intelligence theory, all of these things are complimentary and supplementary to inclusion- so we have to help people see the interconnectedness of that.
- **I have never seen inclusion work for a child or within the system if there is not a strong sense of collaboration.**
- The heart of it all is training. The more we can advocate the preservice change, the more it works.
- Take time to celebrate. Whether you are the teacher or the parent, it is not perfect and we have to keep working toward it. It takes 7-10 times the energy to create positive change as it does to maintain the status quo. I think if we are going to have the energy to do that we better be celebrating the process, the journey as well as the outcomes.

Question: *One of the barriers that we have run into isn't even their lack of education, but their lack of willingness. I know that some of that is fear, but how do we change people's attitudes?*

Continued on page 27

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The 1998 Conference was filled

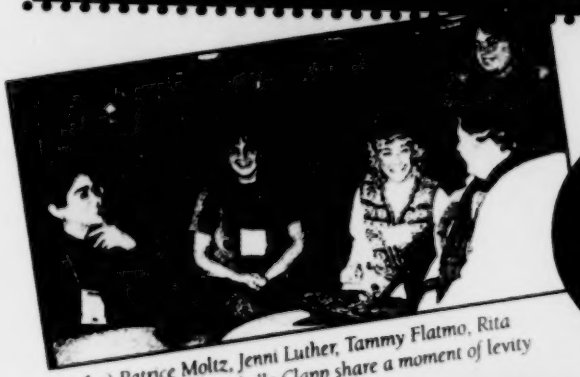
Creating Futures Together

with stimulating and informative workshops...

TASH Conference '98

SEATTLE, WASHINGTON

CONFERENCE HIGHLIGHTS



▲ (l-r) Patrice Moltz, Jenni Luther, Tammy Flatmo, Rita Crossland, and Michelle Clapp share a moment of levity in between sessions.

▲ (l-r) Anne Smith, Norris Haring, and keynote speaker James Banks.

▼ Bob Perske

▶ Students from White River H.S. in Buckley, WA share their CONNECTION Program, designed to foster circles of friends, at a poster session. (l-r) Jennifer Grant, Will Main, Sean Chaussee (standing), Erin Bily, and Donna Daggett.

▶ Steven Elliott, newly-elected president of TASH's Washington State chapter and Susie Schaeffer.

▲ Marc Dubin (l), Bob Williams and Bob's companion, Decoy.

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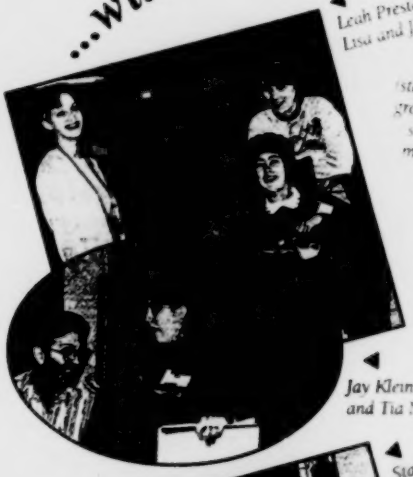
...with time to network and lots of special events, too!



Leah Preston (l) with Lisa and Jane Gilliland

Alan Berger (standing) led a group of hearty souls in early morning yoga activities.

Micah Taylor appeared in person at the media festival screening of "The Flowering of a Child with Disabilities," his father Ron's video-taped journey of Micah's experiences.

Joseph Rennenberg makes sure that there's no peeking as he assists Angie Talcott of Grayline Convention Hosts to draw the name of one of the door prize winners, while Alan King looks on.

Jay Klein and Tia Nelis

Staff and participants enjoyed Club TASH activities.

▲ Club TASH

▲ TASH conferees received greetings from individuals and groups representing many different languages, countries and communication methods.

Conference attendees joined members of the Let's Dance Band as they entertained the audience.

▲ Sharon Jodock-King, one of the speakers at the candlelight vigil

James Meadours, Joe Meadours and Liz Obermayer carried the TASH banner during Friday evenings vigil.

Judith Snow (seated left) and rally announcer Lyle Romer (far right)

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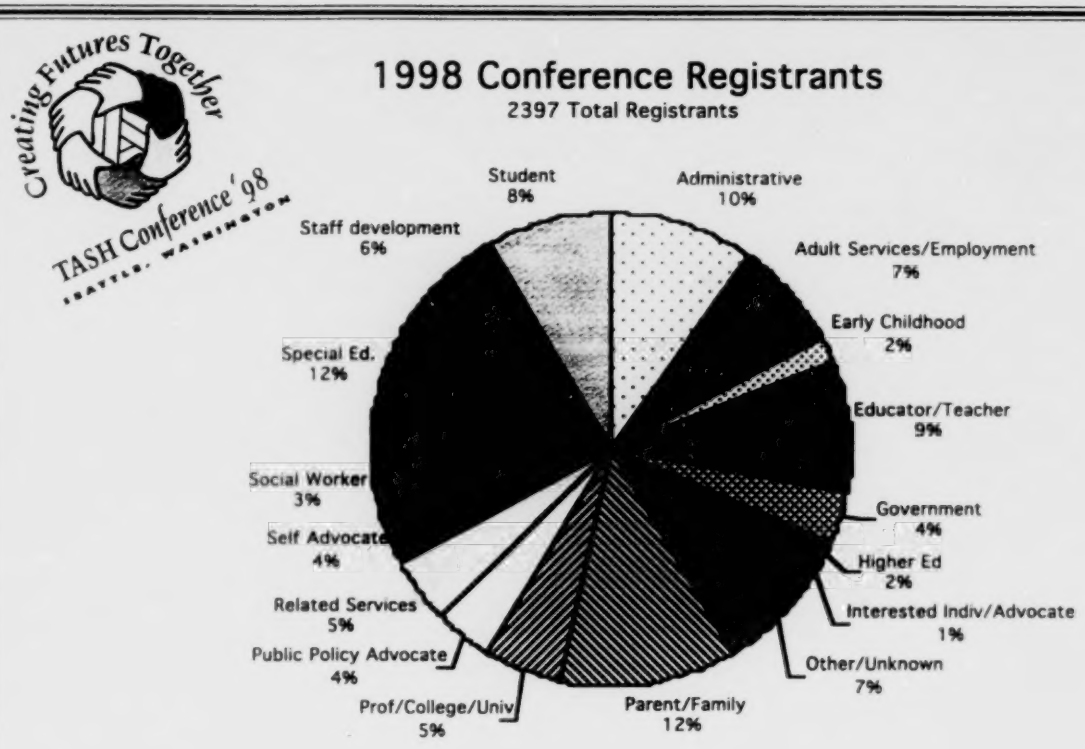

The 1998 TASH Conference, "*Creating Futures Together*", was attended by 2,397 people from all 50 states and the District of Columbia! We also had extensive international representation that included attendees from Australia, Bermuda, Bulgaria, Canada, England, Hong Kong, Japan, Malta, New Zealand, Singapore, Sri Lanka, and Viet Nam.

We knew the Seattle-based event was going to be good when, just as registration officially opened on the first day, the sun broke through the clouds and shone brightly into the atrium of the convention center. That symbol of warmth, energy and optimism exemplifies what many TASH conference attendees fondly refer to as "the spirit of TASH."

That spirit was indeed present in full force this year, with over 470 sessions. Participants rated the sessions as excellent, with professional, expert, and enthusiastic speakers. The highlights of the conference, as evaluated by participants were:

- The quality and variety of sessions offered
- The expertise of the speakers
- Excellent location/facility
- The well-organized logistics of the conference
- The networking opportunities

Many thanks to the conference committee, the presenters, the strand coordinators, the reviewers, the local committee, the exhibitors, the sponsors, the TASH Board and staff, and all of the attendees who make this incredible and ever-growing event so successful. Your efforts and energy sustain many folks throughout the year in their struggles for inclusion and equity for all.

Make your plans now to join us in Chicago, December 8-11, 1999 for the TASH Annual Conference: "*TASH 2000: Our Turn Now.*"

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1998 Keynote Speakers

James Banks

Duane French

Laura Hershey

Sue Rubin

Zuhy Sayeed

Robert Williams

and TASH Award Winners

1998 Positive Approaches Award

Michael Dowling accepted the Positive Approaches Award on Herb Lovett's behalf.

The 1998 Positive Approaches Award was presented to Herb Lovett posthumously in honor of his work, which had a profound influence on the lives of people with disabilities, their family members, supporters, and policy makers around the world. Herb's commitment to people who were routinely punished or hurt in the name of treatment, as well as those who were beginning to take their rightful places as leaders in the self-advocacy movement, will live on in his writings and our hearts.

1998 Thomas G. Haring Award

Glen Dunlap accepts the First Annual Thomas G. Haring Award.

The First Annual Thomas G. Haring Award was given to a group of researchers who conducted two exemplary studies surrounding a single applied problem - how to design an effective intervention that will support the needs of a parent whose child with significant disabilities displays difficult behaviors in community settings. The Haring Award recognized the authors for the quality and significance of their articles on *Parent-Professional Partnership in Behavioral Support* which appeared in the Winter 1997 issue of JASH.

Thomas G. Haring Award Recipients: Bobbie J. Vaughn, Glen Dunlap, Lise Fox, Shelley Clarke and Millie Bucy.

1998 Collaboration Award

This award was given to the team that assisted Waddie Welcome to realize his dream to live within his chosen community. Theirs is an extraordinary story of Waddie's personal mission to leave the nursing home and successfully live in the community. Mr. Welcome's circle of friends listened to him, learned to communicate in his language, and used person-centered planning to enable Mr. Welcome to live in the manner of his choosing.

Collaboration Award Recipients: Waddie Welcome, Deacon Washington Hart, Susan Earl, Emily Earl, Dottie Black, Jane Fishman, Tom Lamar, Hermand and Linda Friedman, W.W. Law, Regina Thomas, Mary Welcome Williams, Margaret Welcome Jackson, Ms. Addie Reeves, Debra Selman, Jackie Immel, Lester Johnson, Naomi Brown, Kathy and Jeff Alden, Clarence Peterson and Tom Kohler

Waddie Welcome (2nd from left) and several members of His Circle of Friends

1998 Media Ward

Although they were unable to be present to accept their award, TASH proudly presented the 1998 Media Award to the investigative team of reporters from the Hartford Courant for their series of articles, *Deadly Restraint: A Hartford Courant Investigative Report*. The series sites the results of a 50-state survey which confirmed 142 deaths in mental health and mental retardation facilities and group homes nationwide over the past decade. The series gave voice to the unheard protest of those individuals who are no longer here to fight on their own behalf.

Media Award Recipients: Dave Altimari, Dwight F. Blint, Kathleen Megan, Eric M. Weiss, and The Hartford Courant

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A 1998 TASH Conference Keynote Address:

ZUHY SAYEED

Zuhy Sayeed and her husband, Raffath, became active in the field of differing abilities in 1982. Today, their dedication to human rights and community living is a family commitment. Zuhy was appointed to the President's Task Force on Inclusive Education and to the United Nations Panel of Experts for the Monitoring and Implementation of the Standard Rules for the Equalization of Opportunities for Persons with Disabilities. Zuhy believes that effective community-building can be achieved through collective advocacy. TASH was honored to host Zuhy Sayeed as one of the keynote speakers during the 1998 Annual Conference. Following are excerpts from her keynote remarks.

Before I begin, I would like to introduce myself and Raffath, as parents, first. All our four sons have taught us so much, and the joys and the challenges of parenting have been augmented by the experiences that have made our family who we are. What I will present to you today is reflective of our family commitment to the movement for inclusion or, as we call it in Canada, the community living movement.

This year, 1998, is the year that the world is reviewing and examining their commitment to the Universal Declaration of Human Rights. Indeed, it is a time to be reflective of the deep commitment to the elimination of horror and discrimination that occurred over 50 years ago. Eleanor Roosevelt and John Humphrey, an American and a Canadian, authored a dream of global, universal protection for all human beings. They were visionaries who realized that in order for sustained, world peace all citizens had to be free, equal and honored.

Fifty years later, the rhetoric of equity, protection and opportunity still exists. There remains a large gap between the promises of the Declaration, our own beliefs and actions, and inclusion of all people within our society. Persons with a developmental disability are among the most marginalized, the poorest and the most discriminated members of their communities. For persons with a disability, their marginalized status is rooted in attitudinal conditions, which are reinforced by political, social, economic and cultural structures, rather than in the nature of their disability. Too often human rights are thought of only in terms of protection from the atrocities of war, repression or discrimination based on traditional thinking.

The Universal Declaration of Human Rights rose from the ashes of the gas chambers of the Second World War. The first victims were persons with disabilities - people whom we often forget in our remembrances. Even today, in all of the recent genocides in war and in situations of natural disasters, persons with disabilities are considered expendable. Society traditionally defends the human rights of people when there have been violations of rights based on gender, poverty, age, religion, race, issues related to aboriginal people and children, justice, effects of war and oppression, employment, education, economic prosperity and health. Even human rights organizations do not include issues of persons with disabilities in their agendas, even though issues relating to persons with a disability cut across all sectors and all walks of life.

Human rights are indivisible. Different sets of human rights do not exist for different people. 1998 is a year that will be marked in the chronicles of history as issues that face persons with developmental disabilities — situations of extreme poverty, neglect, and abuse to name but a few — have finally been officially placed on the agenda of the UN Human Rights Commission. The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, The Salamanca Declaration, UNESCO's clear message and direction on inclusive education, The Managua Declaration — all the UN instruments that promote equity for persons with disabilities — can now be reinforced strongly within our governments and within the special agencies of the UN that work actively in regions around the world.

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Human rights are indivisible. Different sets of human rights do not exist for different people.

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This signifies a progressive shift in thinking – from charity to equity and full citizenship - that parents, advocates, individuals with developmental disabilities and the organizations we belong to, have advocated for over the past 40 years.

In Canada, the Canadian Association for Community Living (CACL) and its provincial and local associations have celebrated 40 years of advocacy. The founding parent association marked its 50th year. Fifty years ago parents gathered around living rooms and informal meeting spaces to give voice to their dreams of equity for their sons and daughters. This national association of parents, professionals, and community advocates has its roots in intellectual disabilities. Today, it is evolving into an association that is committed to creating an inclusive society that celebrates all forms of diversity.

Our international federation, Inclusion International, is a collective of over 179 national organizations representing almost 110 countries. It is one of the six non-governmental organizations (NGOs) that works actively with the UN and other world partners to promote the human rights of persons with developmental disabilities and their families. The

Continued on page 13

Zuhy Sayeed

Continued from page 12

stories we have to share are many. They signify the true experiences that we have had over years of denial and oppression. They demonstrate the injustices and the effects of labeling that have denied opportunity for millions of children and adults with developmental disabilities and relegated them to a life of dependency, segregation and poverty.

Labeling is insidious. It creeps into our lives couched in everyday, seemingly acceptable language. It convinces us that it is the only way that our sons and daughters will have their 'extra ordinary' needs met. It creates a culture and a mindset [of] disability that grips the general public right in the beginning and once that sets in, the mindset is difficult to change. Even our own language creates expectations that have its roots in medical terminology that is unacceptable in today's framework of the human rights of our family members and friends. Labeling seduces us into believing that, once labeled, our children will be "fixed" or "cured" — provided we agree to a life of segregation and the denial of true opportunities to realize the inherent potential that every human being does possess.

I emphasize again that every human being has potential. It is the limitation of opportunity, attitude and the environment that prevent the innate potential of every child and adult with developmental disabilities from being realized. You have seen living proof over the last two days. Real life potential that could have been written off — in Sue [Rubin], in Bob [Williams], in Micah [Taylor].

Bishop Tutu, in his address to the International Conference on Human Rights last week in Canada, spoke about the resilience of the human spirit. Indeed, as parents and advocates of persons with developmental disabilities, we see courage, strength and the perseverance towards a goal demonstrated every day.

Our story began 16 1/2 years ago. Through those years we have seen a child — our child — who couldn't walk or talk, be encouraged to learn sign language. The child we were advised to send away those many years ago is now a young man, full of confidence and way past the prediction of only 'making grade 3 or, at the very most, grade 5.'

• • •

I emphasize again that every human being has potential. It is the limitation of opportunity, attitude and the environment that prevent the innate potential of every child and adult with developmental disabilities from being realized.

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Personally, as parents of two young men with different abilities, I can attest to the fact that the young people around our sons in school, in the community, in scouts, judo and in soccer, have an innate sense of fairness and inclusion. Children don't see differences, they see gifts. As a preschool educator for over 16 years and an elementary school teacher for some years prior to that, I can attest from an educator's point of view, that children are by nature inclusive. I can tell many stories of the unconditional inclusion through the eyes of a young child.

Resistance to successful inclusion has come from schools where teachers had fixed ideas of the disabilities and limitations of their students. We have faced resistance and disbelief before, and will continue to find pockets of fear and lack of awareness and knowledge in our colleagues, peers, and in the community at large until we make real change. Until we demonstrate that persons with developmental disabilities can learn, play, live and contribute meaningfully to their community, their state and their country. Until we speak loudly to the fact that any kind of segregation in our schools, workplaces and in our communities does lead to a lifetime of being set apart, dependency and no contribution. The Canadian Supreme Court decision, unfortunately, has promoted educational apartheid which has encouraged segregated practices in education in the guise of inclusion.

Until we embrace the idea that our world is interdependent and that we all have skills that can be learned to contribute to the richness of this diverse world in many different ways. Until we take responsibility to establish and nurture partnerships and coalitions with human rights organizations and others so that disability issues are inserted into everyone's agendas. Until we become part of the force - not separate - fighting for social justice for all people. For if we continue to separate ourselves, that is what society will perceive our goals to be.

Until we work collectively to overturn repressive laws that are being flaunted as protective laws. The vigil today will mark the advocacy that we must be engaged in here as well as in the communities that we will return to after today. Until we demand real justice for the murders and abuse towards children and adults with developmental disabilities and, in turn, examine the reasons why so many people with developmental disabilities face an unjust legal system.

Until we combat the tired arguments of the "cost factor." The Roeher Institute, CACL's internationally acclaimed research institute on disability and social justice policy, recently participated in a study that researched the cost factor for excluding people. The results of the study reported that not only does denial and segregation cost money, but it also results in huge sums of money in lost productivity. When we all begin to talk in those terms, we will then get attention.

Until we ensure that fast-paced scientific progress includes checks and balances that will preserve and protect the natural diversity of the human race, we will see resistance until then. We will encounter questions and the demands for 'proof' that this 'inclusion' works. The proof is beginning to happen, but only because a small group of us are insisting that labels kill the chances of our children being treated as full citizens, and that despite labels and traditional thinking, we *will* insist that our children be included in every aspect of community life. We are pushing the envelope so that the proof will be there for the future

Continued on page 14

Zuhy Sayeed

Continued from page 13

And we welcome the partnerships we have here today which will make that happen. As parents it is our role to fulfill our dreams and to let our children dream their dreams. For as it has been said, without dreams, nothing happens.

All families need warmth and protection to carry out the precious roles of bringing up children, all of whom teach us valuable lessons. Lessons of hope, of joy, of strength and indomitable courage in the face of the harshness of the world. Our children prove to us that even in the most challenging situations, there is always joy and learning.

Raffath and I firmly believe that as parents and community members we play a dual role in bringing up not only our children, but also raising the communities in which we want our children to live. Our communities need leaders with vision, with understanding that everyone's contributions are vital to healthy, peaceful countries. I realized a few years ago as I engaged in conversations and discussions in hockey rinks and on soccer fields, and in the course of parent volunteering in schools and at community events, that the community at large is us — all of us. We hold the key to inclusion and welcoming our sons, daughters, students or friends. That it is our responsibility to create an environment where abilities and strengths matter.

We must work to create an environment that says the accommodations of the past have been limited to surface adjustments. That nothing will change if we continue to focus on the limitations of persons with a disability instead of the limitations within our communities, systems, laws, policies and programs. Instead of continuing to segregate and isolate persons with disabilities, we should be engaged in work that benefits all people in our communities.

Including people with disabilities has taught us valuable lessons. It has also made us, as citizens, realize that it is only a matter of time before we, too, will have the need for warm, welcoming, accessible and inclusive communities.

We know that the human race is glorious in its diversity. That our children, who have the opportunity to grow up with their peers and with all the threads of the fabric of a community, will grow to be the future leaders and the citizens of tomorrow. It will be this generation of leaders who will look for ways to embrace the strengths and the skills of all of their friends.

• • •

As parents and community members we play a dual role in bringing up not only our children, but also raising the communities in which we want our children to live.

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The challenge to us, who will take messages from TASH to the world, is to find ways as educators, parents and advocates to assist the education system to take advantage of being poised for making real change in the future. You, who are enlightened, know that education is the key to break the cycle of marginalization and discrimination. Education by its very nature has the potential to improve the social and economic status of individuals with disabilities. Those who now possess the skills are in the position to make changes that improve socio-economic status which lessens marginalization.

It is the responsibility of the education system and the community at large to change true attitudinal prejudice. All the change agents are in place. It is evident at this gathering. The ideas and strategies shared here speak to real inclusion- as is the belief and the commitment to the inherent potential that is in us all. It is the education system that guides our learning and should emulate the role models provided by children. It is our role as citizens to foster a civil society that will be good for us all; one that is truly inclusive of all the abilities and strengths of all people. There is so much work to do.

All over the world, the potential of persons with disabilities is being realized, and the lessons of inclusion are being noticed.

Inclusion — the word itself conjures a picture of belonging, of being part of woven threads of colorful fabric which are the communities we live in. Not separate, not apart, not in expensive, special systems that will be unsustainable and ineffective in the end. Rather, together as one community and as one people as we were meant to be. Abraham Lincoln said, " ...All men are considered equal..." It is only this inclusion, this complete belonging together in all our glorious diversity, that will promote the full participation and the celebration of our strengths in the world of tomorrow.

No other concept of inclusion will lead to full citizenship. It will only lead to future educators, parents and persons with disabilities having the same conversations 50 years from today. It will continue to lead two systems of education, which will not lead to an inclusive society.

Nothing would have changed. Nothing would have harnessed the energy and the conviction in this room today and in many such rooms around the world. The time is right. The time is now. Let us put aside our own traditional notions about the worth of people and let us give our children a chance. They will prove to us that true inclusion of persons with developmental disabilities will create futures together. A future that holds a promise of equality and citizenship, remembering that the rights of man come not from the generosity of the state, but from the hand of God.

• • •

It is the responsibility of the education system and the community at large to change true attitudinal prejudice. All the change agents are in place. It is evident at this gathering. The ideas and strategies shared here speak to real inclusion.

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TASH 2000: Our Turn Now

Call for Presentations

International TASH Conference
December 8-11, 1999
(Pre-Conference Workshops & Opening Reception on December 8th)

***TASH** is an international advocacy association of people with disabilities, their family members, community members, other advocates, and people who work in the disability field. Our members are fighting for a society in which inclusion of all people in all aspects of society is the norm. We are an organization of members concerned with equity, diversity, social justice, human rights, and inclusion for all.*

Send the Original and 3 copies of the Application and Abstract (postmarked) by March 22, 1999 to:

Kelly Nelson, TASH , 29 West Susquehanna Avenue, Suite 210, Baltimore, MD 21204

Questions? Phone: 410-828-8274 ❖ TDD 410-828-1306 ❖ Website: http://www.tash.org

Sorry, faxed or e-mailed copies cannot be accepted

1999 Priority Topics

Proposals may be submitted on any topic that relates to the inclusion of people with disabilities. The 1999 Conference Committee has identified particular interest in the sub-topic areas listed below:

Advocacy
Building Alliances and Coalitions
Community Living
*Creative and Performing Arts
Communication
Criminal Justice
Curriculum Adaptation
Deaf Culture
Dual Sensory Impairment
Early Childhood
Educational Reform
Employment and Careers
Family Issues
Functional Assessment for Behavior Change
Governmental Affairs
Grassroots Organizing
Guardianship
Higher Education
International Inclusion
High School Inclusion
Housing /Home of Your Own
IDEA Monitoring and Enforcement
IDEA '97 Regulations
Impacting Legislation
Inclusive Education Strategies
Independent Living Centers, Councils, or Services
Integrated Sports
Internet and Disability
Issues of Death and Dying
Issues of World Peace & Social Change
Leisure and Recreation
Life Transitions & Changes in Supports for Aging Adults
Managed Care
Management Issues
Mediation
MiCASA/Personal Assistance
Multicultural Issues
Paraprofessional Issues
Personnel Preparation
Positive Approaches to Behavior Change
Qualitative & Quantitative Research
Rare Syndromes
Rehab Act
Related Services in Inclusive Education
Self-Advocacy
Self-Determination
Special Health Care in Inclusive Settings
Sexuality, Romance, & Dating
Spirituality
Teacher Preparation
Transition from School to Work
Special Health Care Needs
Students Who Severely Challenge Schools
Systems Change at the Local Level
Systems Change at the Policy Level
Urban Education Issues

** Please note: TASH will not be able to provide staging, lighting, etc. in session rooms.*

Guidelines for Submission

1) **TASH encourages presentations that are made through partnerships.** Panels are also encouraged to represent multicultural, under-served, and varying socioeconomic viewpoints. Presentations for consideration in the the Community Living Strand will *require* participation of self-advocates and/or family members for acceptance.

2) **An abstract must be sent along with the completed application, postmarked by March 22, 1999.** Abstracts should (1) describe the topic or issue addressed, (2) provide an overview of the content, (3) describe the importance and contributions of the session, and (4) describe the session format - i.e. skill-building, program discussion, panel, etc.

3) **Proposal content must reflect the values and resolutions of TASH**. TASH is dedicated to disseminating information that reflects both the ideals and the pragmatic realities of pursuing the goals of equity, social justice, diversity, and full community participation for people with disabilities. The proposal title, description, and all content of presentations must use "people first" language, and must relate to supports or issues that are community-based.

4) **Please limit the abstract to 300-600 words (1 - 1 1/2 pages).** Do not send any other materials. You may submit the information on the application form or in alternate format, as long as all of the information requested is included. The form is available to download from TASH's web page: www.tash.org. You must, however, print and mail the form as per the guidelines. Please **DO NOT** email your proposal, as we cannot assure receipt or legibility of electronic transmissions.

5) **Please complete all sections of the form:** coordinator information, session description, and contact information for co-presenters. TASH encourages you to include a variety of co-presenters in your sessions. Please include presenters who are reasonably certain of attending. Copy the co-presenter form if necessary.

6) In requesting the session format, please keep in mind that 1 hour and 2 1/4 hour presentations are reserved for interactive workshops with an audience. **Poster sessions are table top "exhibits" that allow personalized opportunity for discussion.** These sessions are highly interactive and valuable.

7) ***All* presenters are required to pay conference registration fees.** TASH relies soley on membership and conference registration to be an effective advocacy organization. We strongly encourage presenters to be TASH members. TASH members, self-advocates, parents, and family members are eligible to register at a reduced rate.

8) Once received, abstracts are forwarded to three reviewers for scoring. **Proposals are rated on the following criteria:** 1) relevance to TASH mission, 2) interest to TASH members, 3) exent to which information is state-of-the-art, or cutting-edge, 4) the practicality of content, and 5) the clarity of the proposal. Scores are then tallied and ranked.

9) **A basic package of audiovisual equipment will be available in all session rooms at no charge to presenters this year.** This package includes an overhead projector and an 8x8 screen. If you require additional equipment (such as a slide projector, flipchart or markers, or TV/VCR), you may rent the equipment for the specified cost. Order forms for audiovisual equipment will be sent with acceptance letters.

10) At times letters of acceptance get lost, or go to an incorrect address. **Letters indicating if proposals have been accepted are sent in August.** Do not assume that your proposal has not been accepted if you do not receive a letter. Call the office to check on the status of your proposal. **Letters are sent to the coordinator** to indicate if accepted or not accepted. It is the responsibility of the session coordinator to notify co-presenters of acceptance.

11) **If accepted, you may not receive the session time frame or format you requested.** Session assignments are based on the recommendations of reviewers, with final approval by the conference committee. Your session may be accepted as part of an In-focus Strand or as part of a general listing of sessions. The specific session room will be scheduled closer to the date of the conference.

12) **All presenters are required to make the material for their session available in alternate format.** Information on accessible formatting will be provided with letters of acceptance.

13) **A selection of conference sessions will be audiotaped.** This will allow sessions to be available in an alternate format to those who request tapes of session, or to be available electronically (when paying a registration fee) or for sale post-conference. Please be sure to indicate on the application if you agree to be considered to participate in having your session taped.

The 1999 TASH Call for Presentations is available in alternate format upon request.

1999 TASH Conference Presentation Application

(please be sure a one page abstract is attached to this form)

Date Received: _____

Session Code: _____

SESSION COORDINATOR (1 person only): _____

Please list below the address which you would like in the conference program:

ORGANIZATION: _____

ADDRESS: _____ CITY: _____

STATE/PROVINCE: _____ COUNTRY: _____ ZIP/POSTAL CODE: _____

DAYTIME PHONE: _____ HOME PHONE: _____

FAX: _____ E-MAIL: _____

The above address is: ❒ HOME ❒ WORK ❒ OTHER _____

Please send my letter which indicates acceptance status to:

❒ Same as Above (*skip the next session if checked*) ❒ Use Different Address (*please list below*)

ORGANIZATION: _____

ADDRESS: _____ CITY: _____

STATE/PROVINCE: _____ COUNTRY: _____ ZIP/POSTAL CODE: _____

DAYTIME PHONE: _____ HOME PHONE: _____

FAX: _____ E-MAIL: _____

The above address is: ❒ HOME ❒ WORK ❒ OTHER _____

Session Information

SESSION TITLE (*please do not exceed 10 words*):

_____

❒ If accepted, I agree to allow this session to be taped. (*See Guidelines for Submission*).

❒ If accepted I **Do Not** want this session to be taped.

Signature _____

Please type a description of your presentation in 40 words or less. This description will be reprinted in the final Conference Program if accepted. TASH reserves the right to edit descriptions. Please include information on content and format of session.

Requested Session Type:

(Please check only one)

- ❒ 1 HOUR SESSION
- ❒ 2 HOUR & 15 MINUTE SESSION
- ❒ POSTER SESSION
- ❒ TASH TECH (Pre-Conference Workshops)

Applicable Interest Area

(This category determines which committee reviews your proposal. Please pick only one)

- ❒ ADVOCACY
- ❒ AGING
- ❒ ASSISTIVE TECHNOLOGY
- ❒ CREATIVE/PERFORMING ARTS
- ❒ COMMUNICATION
- ❒ COMMUNITY LIVING/HOUSING
- ❒ CRIMINAL JUSTICE
- ❒ INCLUSIVE EDUCATION
- ❒ INDEPENDENT LIVING
- ❒ EARLY CHILDHOOD
- ❒ EMPLOYMENT AND CAREERS
- ❒ ETHICS/RIGHTS
- ❒ FAMILY
- ❒ GOVERNMENTAL AFFAIRS
- ❒ HIGHER EDUCATION
- ❒ LEISURE AND RECREATION
- ❒ MANAGEMENT ISSUES
- ❒ MULTICULTURAL/INTERNATIONAL
- ❒ PARAPROFESSIONAL
- ❒ PERSONNEL PREPARATION
- ❒ POSITIVE APPROACHES
- ❒ RELATED SERVICES
- ❒ RESEARCH
- ❒ SELF-DETERMINATION
- ❒ SPECIAL HEALTH CARE NEEDS
- ❒ SPIRITUALITY
- ❒ SEXUALITY/ SEXUAL EXPRESSION
- ❒ STUDENTS WHO SEVERELY CHALLENGE SCHOOLS
- ❒ TRANSITION
- ❒ URBAN ISSUES

Co-Presenter Information

NAME: _____

ORGANIZATION: _____

ADDRESS: _____ CITY: _____

STATE/PROVINCE: _____ COUNTRY: _____ ZIP/POSTAL CODE: _____

DAYTIME PHONE: _____ HOME PHONE: _____

FAX: _____ E-MAIL: _____

The above address is: ❒ HOME ❒ WORK ❒ OTHER _____

NAME: _____

ORGANIZATION: _____

ADDRESS: _____ CITY: _____

STATE/PROVINCE: _____ COUNTRY: _____ ZIP/POSTAL CODE: _____

DAYTIME PHONE: _____ HOME PHONE: _____

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DAYTIME PHONE: _____ HOME PHONE: _____

FAX: _____ E-MAIL: _____

The above address is: ❒ HOME ❒ WORK ❒ OTHER _____

Thank you for your interest in presenting at the 1999 International TASH Conference

Copy this page for additional presenters. Pass a copy of the entire application to a friend or colleague!

Director of Supported Employment
Personalized Day Supports

Jay Nolan Community Services is looking to hire an outstanding leader in the field of developmental disabilities to join our team. Our commitment is providing state of the art supports to people with autism and others who may need positive behavioral supports in order to work and lead interesting and valued lives in the community.

The ideal candidate will have a strong value base in the field of supported employment and personalized day supports. Position requires work history of individualized placements, entrepreneurial endeavors, knowledge of person-centered planning and circles of support. Must share our commitment to excellence, to listening to people with developmental disabilities, and to creating a team atmosphere.

Salary range: $45-55K. Excellent benefit package. Please send resume to:

Jopie Smith, Assistant Executive Director
Jay Nolan Community Services
15501 San Fernando Mission Blvd., Suite 200
Mission Hills, CA 91345
Fax: 818/365-0522; e-mail: jopie@jaynolan.org

Innovations
Invitation for Submissions

ABOUT THE SERIES

Innovations is a publication of the American Association on Mental Retardation that brings research to practice. Designed for busy practitioners, **Innovations** translates research findings into clear, usable ideas. Each issue is devoted to one topic. Recent issues have included:

Teaching Students in Inclusive Settings	by MaryAnn Demchak
Teaching Self-Management to Elementary Students	by King-Sears & Carpenter
Designing Positive Behavioral Support Plans	by Bambara & Knoster
Increasing Variety in Adult Life	by Daniel Steere

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CALL FOR CONTRIBUTORS

Submissions of proposals for the 1999 series are invited. Potential contributors are requested to prepare a 2-3 page proposal, including a description of the topic and its importance, an outline of the content and references. If a proposal is accepted, a full manuscript will be invited for review. The deadline for the next round of review is **May 1, 1999**. Mail 15 copies of the proposal to Diane Browder, Editor of Innovations, Department of Counseling, Special Education, and Child Development, University of North Carolina at Charlotte, 9201 University City Boulevard, Charlotte, NC 28223-0001.

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We welcomed several new exhibitors to the 1998 conference and we hope they enjoyed being a part of the TASH event as much as we enjoyed having them. We also take this opportunity to salute those exhibitors we have had the pleasure to work with over the years. Your loyalty and support is greatly appreciated. Thanks to all of the individuals and companies that helped to make the 1998 conference a success! We look forward to welcoming you back with us in Chicago in December!

1998 Conference Exhibitors

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Bridge Ministries for Disability Concerns
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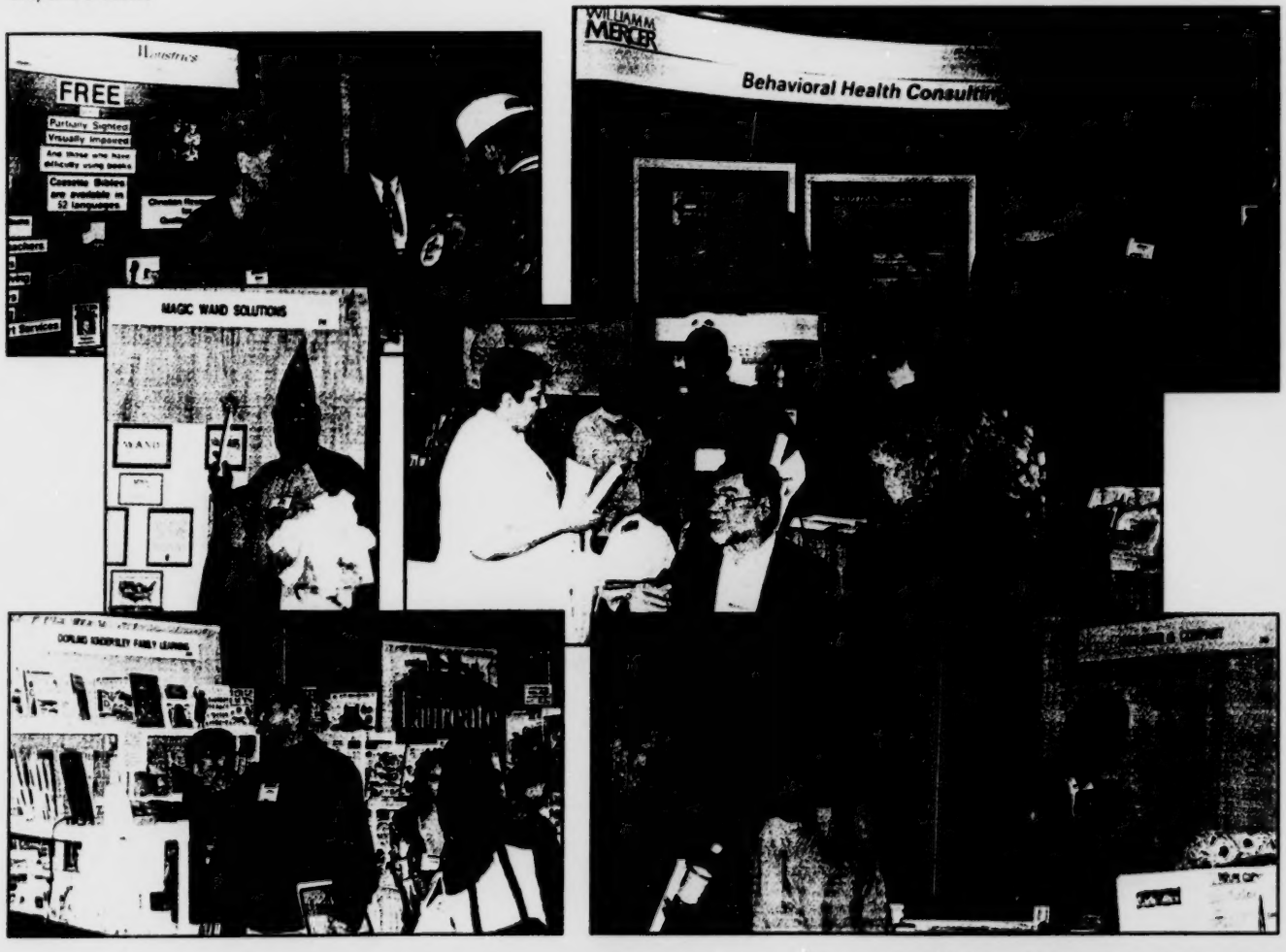

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KEYNOTE REMARKS:

LAURA HERSHEY

It is really great to be here. It's great to look around and see so many diverse individuals doing really important work in such diverse ways. It's experiences like this one that make me really happy to be a part of the disability community and to be part of a movement which is actually a lot of little movements. [The movements are] a lot of efforts that sometimes are in conflict with each other, sometimes go in different directions, sometimes agree, sometimes don't. But it's all great because all of you, all of us, are working in the ways that make the most sense to each person to make this world a better and more just place for people with disabilities.

I started thinking a lot recently after the arrest of General Pinochet. That event has kind of raised hopes for human rights advocates all around the world. People are waiting and watching to see whether the international legal systems will finally bring this man to justice. If you don't know, Pinochet is the former Chilean dictator who was responsible for a lot of terrible crimes against his own people. Under the Pinochet government, which was supported financially and militarily by the United States, tens of thousands of Chilean activists and other people disappeared. He "disappeared" them. The grammar here is intentional. These people, they disappeared – went missing. But they didn't just disappear. They were disappeared. They were deliberately and forcibly made to vanish – into hidden places and unknown fates. Fates that usually included imprisonment, torture, and/or murder. These atrocities occurred in secret, out of public view, so that accountability was impossible, so that knowledge could be denied, and so that even outrage was butted. It's hard to sustain anger or incite protests over crimes that you can not see.

I bring this up for a reason. **I really see a parallel between "the disappeared" political prisoners of Latin America and untold numbers of people with disabilities in our own country. In so many different ways, masses of our people have been disappeared, too. They have been removed from view, sent away to places where they can not be seen, or they can not be heard from, or where they can not be embraced or protected by the community.** Isolated and invisible, these people have been subject to the whims and actions of people who have power over them. They've been, in effect, held prisoner and stripped of any power of their own. They've been disappeared, but it's often harder, even for us, to organize around opposing that because there is no single dictator that we can point to who has mandated or orchestrated these atrocities.

These disappearances have happened in our democratic country. Things like that are not supposed to happen here, but they do. They have happened throughout history, and are continuing to happen. They're still happening.

The good news is that there are a lot of resistance movements. Just like the human rights activists in Latin America fighting against the disappearance of their loved ones, we, the disability rights movement, are the resistance movement, fighting against the disappearances of our loved ones, many of whom we don't even know. But we are committed to them.

I'm just going to talk about a few of the ways that people with disabilities in this country are disappeared; and a few of the ways that people with disabilities and our allies are fighting against that. Segregated, so-called "special" schools and self-contained classrooms "disappear" our children with disabilities – depriving them of a place in society, and depriving society of them. But organizations like TASH, like PEAK Parent Center in Colorado, and many, many others, are fighting back against the disappearance of children with disabilities from our schools. It's a battle we haven't won yet. It's one that must continue for a long time. We are fighting it hard in the legislative arena with Congress, with the recent battles over the reauthorization of IDEA. We also must fight it every single day, in every classroom, in every school, in every district.

Another form of disappearance of people with disabilities is nursing homes and other institutions. These institutions "disappear" people of all ages who happen to need some kind of support and assistance in order to survive. This is wrong. I think we have to say, always, that it's wrong at any age. Institutionalization is wrong for our children; it's wrong for ourselves and our brothers and sisters. It's also wrong for our parents and our grandparents and it has to stop. The resistance movement is being spearheaded by ADAPT and the battle for MiCASA. We need to all join that battle. We need to [alleviate] the option to lock people up when they get old and need help or when they are young and need help.

Another form of disappearance which is really insidious and hard to see, is the move to cut federal safety-net programs. Every time I visit Washington, DC I hear more and more about this. I think it's still a little bit behind the scenes, but it's something that is a grave danger. Right-wing forces in the Congress are threatening to strip away some of the basic benefits that we assume are going to be there to provide support to the poorest of the poor in our communities. These cuts threaten to "disappear" millions of Americans into poverty and homelessness. As Ghandi said, "Poverty is a form of violence."

These cuts are also accompanied by the lie that annihilating these programs and these people will save money for the taxpayers. This isn't true. This money will be transferred to corporate subsidies, military procurement, and other programs that benefit the rich. If you want to learn more about that, I would like to recommend a book. I learned from the speaker yesterday, it's a good idea to give a reading list. There's a book called *Beyond Ramps: Disability at the End of the Social Contract* by Marta Russell, and it should be required reading for everyone. It's published by Common Courage Press. Please ask your local bookstore to order it. It's a fantastic book; and it's another example of the resistance movement and the fighting back against the disappearances of our very poor brothers and sisters with disabilities, many of whom are truly are on the verge of homelessness. Some of them are already there, and many more will be if these politi-

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Laura Hershey

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cal movements succeed.

Another form of the disappearance of people with disabilities has already been mentioned a couple of times today. It is the move to legalize assisted suicide. This movement comes as part of a broader movement to "disappear" people with disabilities. As profit-driven corporations increasingly monopolize health care dollars, both public and private, those with expensive and ongoing conditions are seen as a drain on society, or on the corporate coffers, and are targeted for elimination. And what better way to do this than through assisted suicide — through the legalization and the funding of assisted suicide. This practice, which should evoke outrage from liberals and progressives, and certainly from advocates of economic justice and human rights, is instead gaining acceptance among these groups. I think that's because of two reasons: one, because the practice is reserved exclusively for the most devalued groups in society – the sick and the disabled. Two, it is covered over with a thin deceptive veneer of voluntariness. Many people accept this lie – that it is about choice. To see the reality of [what is actually happening] you needn't look any further than the state neighboring this one – Oregon.

In Oregon, the state Medicaid system has recently discontinued paying for some pain medicines which are essential for the quality of life of people with certain disabilities, such as MS. Yet, that state Medicaid system will happily pay to end the life a disabled person driven mad by untreated pain. The good news is there is a resistance movement against [assisted suicide] too. We all know what that is – it's Not Dead Yet! I really encourage you to visit the Not Dead Yet! booth down in the exhibit area. And please, if you're uncertain about the issue, or you think you agree with Dr. Kevorkian or with any of the pro-assisted suicide movements, stop by the booth and just read. There's a lot of material there that you can read, and if you educate yourselves, you may start to look at things differently.

Another type of disappearance, perhaps less lethal, but nevertheless important for the long-term gains of our community, is that even the disability advocacy community has, at different times, disappeared people with disabilities. **Every time we accept the assumption that professionals or parents or anybody else can represent people with disabilities' interests better than we represent ourselves, we allow important voices to be silenced.** We allow potentially powerful self-advocates to be disappeared. I'm definitely all for working with family members, friends, service providers, and other genuine allies, but I think it's really important that we learn to recognize when the power imbalances that are out there in society are mirrored within our own organizations. We need to learn to challenge these imbalances in our own organization.

Groups like People First and Self-Advocates Becoming Empowered and other parts of the self-advocacy movement really are the resistance to this kind of disappearance. They've done a tremendous amount of organizing and education among their own communities so that they can begin to take on the leadership roles within these organizations and within the movement. I would strongly encourage all disability organizations, including TASH, to strive not just to have a few people with disabilities on the Board of Directors and other governing bodies, but have a majority of people with disabilities.

So we can see from these examples, there's a strong and dynamic movement of people with disabilities. Lots of movements. It needs to keep growing. It needs to keep going on. I think the keys to resistance and continuing the movement are visibility, collective action, and pride. Visibility is about not being willing to take a back seat, and not being willing to be "disappeared." For example, when Not Dead Yet! does a protest, we're doing more than just arguing a point about assisted suicide. We're actually, by our physical presence at those forums, we're refusing to be gone. We're refusing to be abolished.

The second key is collective action. This is really an important one. I think in our country oftentimes we're taught it's only the individual that matters. Remember one speaker yesterday was talking about the myths that have grown up around Rosa Parks. We've been taught that she was sort of a tired person who happened to be on a bus one day and just didn't feel like getting up and going to the back of the bus, so she refused. As the speaker pointed out, that was not the case at all. Rosa Parks was a dedicated activist and part of a strong tradition and organized movement for civil rights. I think the reason we've been taught these myths in schools and elsewhere, is that it's sort of this divide and conquer mentality. The powers that be want us to think that we should try to do everything ourselves, alone, as individuals. In fact it is collective action that really makes collective change, and social change. I saw a great bumper sticker recently. You've all seen the bumper stickers that say, "Practice random kindness and senseless acts of beauty." Well this bumper sticker was sort of a rebuttal to that. It said, "Practice planned resistance and organized acts of rebellion." I like that. So by all means, **express yourselves individually; express your own creativity and your own ideas. That will give strength to the movement. But collective action – the strong organized action of all those dynamic, creative individuals – will multiply our power more in untold ways.**

I wrote [a poem] over five years ago now. It was a poem that was inspired by a conversation with a woman with a disability. She happened to see a video that was made by a group in Oregon. I don't remember who, but if any of you were involved in it you can be really pleased with yourselves because this woman said, after seeing the video, "This is the first time, since I have been disabled, that I have felt proud." I felt really sad when she said that because, talk about a civil right, a human right. That's something that everybody should have a right to. I started asking myself why this happens. I started recognizing it happens in all of us. Not just someone who's never been proud, but there's all kinds of forces that would make us doubt ourselves.

So I wrote this poem. I've read it probably more than any of my other poems. And I've read it to groups of people with disabilities. I've read at gay and lesbian pride marches. I've read it for incest survivors. I've read it for high school groups. And everybody has their own response to it. I've learned so much by reading this poem to groups about the kinds of challenges that we all face, and that threaten to divide, but actually should unify all of us.

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Laura Hershey

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The poem is called: *"You Get Proud By Practicing."*

If you are not proud for who you are or what you say, for how you look,
If every time you stop to think of yourself, you do not see yourself glowing with golden light
Do not, therefore, give up on yourself.
You can get proud.
You do not need a better body, a purer spirit, or a Ph.D. to be proud.
You do not need a lot of money, a handsome boyfriend, or a nice car.
You do not need to be able to walk, or see, or hear, or use big complicated words
Or do any of the things that you just can't do to be proud.
A case worker can not make you proud, or a doctor.
You only need more practice.
You get proud by practicing.
There are many, many ways to get proud.
You can try riding a horse, or skiing on one leg, or playing a guitar
And do well, or not so well
And be glad you tried either way.
You can show something you've made to someone you respect
And be happy with it, no matter what they say.
You can say what you think though you know other people do not think the same way.
And you can keep saying it, even if they tell you you are crazy.
You can add your voice all night to the voices of a hundred and fifty others
In a circle around a jailhouse where your brothers and sisters are being held
For blocking buses with no lifts;

Or you can be one of the ones inside the jailhouse, knowing of the circle outside.
You can speak your love to a friend without fear.
You can find someone who will listen to you, without judging you, or doubting you or being afraid of you
And let you hear yourself, perhaps for the first time.

These are all ways of getting proud.
None of them are easy, but all of them are possible.
You can do all of these things, or just one of them again and again.
You get proud by practicing.

Power makes you proud, and power comes in many fine forms
Simple and rich as butterfly wings.
It is music when you practice opening your mouth and liking what you hear,
Because it is the sound of your own true voice.

It is sunlight when you practice seeing strength and beauty in everyone, including yourself.
It is dance when you practice knowing that what you do, and the way you do it, is the right way for you,
And can't be called wrong.

All these hold more power than weapons, or money, or lives.
All these practices bring power, and power makes you proud.
You get proud by practicing.

Remember, you weren't the one who made you ashamed, but you are the one who can make you proud.
Just practice. Practice until you get proud.
And once you are proud, keep practicing so you won't forget.
You get proud by practicing.

Laura is a disability rights leader, poet, writer and trainer. She educates and agitates whenever possible to promote the rights of people with disabilities. She has organized social change campaigns and events around issues such as Social Security work disincentives, economic justice, and disabled women's leadership development. Laura lives in Denver, Colorado with her partner, Robin Stephens, and their dog and cat.

Posters of Laura's poem, "You Get Proud By Practicing," are available for $10 (includes shipping) and can be ordered directly from Laura Hershey, P.O. Box 9004, Denver, CO 80209. Also, check out Laura's poetry audiotapes at http://ourworld.compuserve.com/homepages/LauraHershey/order.htm

1998 TASH ANNUAL CONFERENCE

TASH gratefully acknowledges the assistance, support and generosity of the following participating organizations:

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Over-Representation of Black Students in Special Education: Problem or Symptom?

Some 5.1 million students, ages 6-21, in the nation's public schools are identified as "disabled" and are served in programs or services called "special education." While such programs have been in place in one or another public school system since the mid-19th century, only in 1975, with passage of P.L. 94-142 ("The Education for All Handicapped Children Act"), were all students with disabilities guaranteed a free appropriate public education.

In the 20 years since P.L. 94-142 has been fully implemented, the number of students served has increased by more than 1.5 million. They now comprise nearly 11% of public school students. While the law identifies 13 disability conditions, 91% of the students fall into one of four categories: specific learning disabilities (51.2%), speech or language impairments (20.2%), mental retardation (11.5%) or serious emotional disturbance (8.6%).

Of great concern is the fact that Black students are significantly overrepresented in the Mentally Retarded (MR) and Severely Emotionally Disturbed (SED) categories. U.S. Department of Education Office of Civil Rights (OCR) data indicate that in 1994 Black students comprised 17% of the overall public school population. However, Blacks represented 25% of students labeled MR and 31% of students labeled SED. (Among Hispanic students, there is under-representation within these same categories: Hispanic students comprised 17% of the overall student population, but only 8% of those labeled MR and 8% of those labeled SED. Asian American/Pacific Islander students similarly were under-represented in these two disability categories. Underrepresentation presents a different set of problems that must be faced.)

This raises serious questions about misidentification, misclassification or inappropriate placement in special education programs and classes. There is both stigma and penalty that may attach to this labeling and categorization, all the greater for just those categories where Black students are most over-represented. Additionally, issues of racial segregation are raised, as most special education classes are separate from regular classes and those categories where Blacks are over-represented are most likely to wind up in separate classes. While 55% of the students in special education programs in the 1994-95 school year were placed in other than regular classes (itself a profoundly disturbing matter), 91% of the students labeled MR and 88% of the students labeled SED were placed outside of regular classes.

Not only are Black students segregated from the general education population in self-contained special education classes, substantial research indicates that these are classrooms characterized by lower expectations; curricula that are less demanding than those taught to students in general; and lesser outcomes (student learning, dropout rates, graduation rates, postsecondary education and employment, living in the community).

The special education system first disproportionately identifies Black and poor youth as "losers," and then promotes their failure in a separate special education system.

What Should Be Done?

These are not issues of recent date. A quarter of a century ago, as Congress considered what became P.L. 94-142, the over-representation of Black students was recognized as a problem. Court suits found over-representation, and in California barred the use of IQ tests for identifying students with mental retardation. P.L. 94-142 itself required the use of non-discriminatory screening instruments. Yet the problem continues. Indeed, in the 1997 reauthorized law, P.L. 105-17, "Individuals with Disabilities Education Act" (IDEA), there are new provisions requiring a determination by each state as to whether significant racial disparities exist in the identification, placement, suspension and expulsion of students with disabilities. When disparities do exist (and Department of Education data indicate wide variances in state practices: for example, in five states more than a third of Black special education students are classified as mentally retarded, while in five other states fewer than a tenth are so labeled), states must develop remedial plans.

A 1998 conference convened by the National Center on Educational Restructuring and Inclusion (NCERI) brought together educators (both general and special education), civil rights and disability rights advocates to address these racial disparities in education and identify strategies for change. Recommendations addressed three sets of issues: 1. Implementing the new federal data collection requirements; 2. Direct and immediate steps to address over-representation; and 3. Systemic changes.

1. Implementing the new federal data collection requirements

While the federal government has

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With the first *Newsletter* of 1999, we are introducing a regular feature called "The Education Corner." Articles that appear in this section are designed to inform and enlighten on a number of education-related topics including: evaluations and assessments; inclusion of students with disabilities in content areas; enforcement of IDEA; standards and best practices; and many other topics.

If you would like to submit an article for consideration, send it via e-mail to pnewton@tash.org

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Over-Representation of Black Students in Special Education

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had responsibility and authority (under Section 504 of the Rehabilitation Act of 1973, Title II of the Americans with Disabilities Act and Title VI of the Civil Rights Act of 1964) to address issues of disproportionate identification, classification and placement, the provisions of the reauthorized IDEA give added authority and impetus to address these issues. But to do so, the federal government, particularly OCR and the Office of Special Education Programs, needs to require data from state education departments disaggregated by disability category and size of school district, as well as assure that data give an accurate picture of student placement. For example, in its current data collection, the Department of Education categorizes as a placement in "regular classes" students who spend as much as 20% of their time outside of such classes, i.e., in a more restricted placement. Further, each state should be required to identify the local school districts at the extremes - that is, by race, the greatest and smallest percentage of students classified as disabled, served in inclusive settings, graduated and suspended. Better data collection and rigorous enforcement are obligations of both the federal and state agencies.

2. Direct and immediate steps to address over-representation

As Patricia Kirkpatrick pointed out in her May/June 1994 P&R article, "Triple Jeopardy: Disability, Race & Poverty in America," while mental retardation can be caused by poverty conditions, "the greater number of black children in special education cannot be explained solely by socioeconomic factors." The inability of schools to successfully educate African-American students, especially males, is especially significant in special education. James Ysseldyke, a leading expert on referral and assessment, stated in a 1993 *NY Times* article, "Studies show teachers refer kids who bother them, and we've been able to demonstrate that specifically African American males demonstrate behavior that bothers teachers."

The system that is used to determine whether a student is disabled and in need of special education services relies heavily upon standardized tests, particularly so-called intelligence tests. Such tests not only implicate racial and ethnic discrimination; they are based on an erroneous understanding of intelligence, as a fixed and largely heritable characteristic, that can be precisely measured and provide an accurate predictor as to one's future success in school and life. Thus, the first immediate step must address the inadequacies of the referral and assessment process, as well as the inappropriate tests. (In the right direction is the development of a Test Resource Guide by the New York City Public Schools, which identifies the appropriateness of tests for particular groups and purposes.)

The National Association of State Directors of Special Education has been addressing the issue of racial disparity for many years. A report from its Project FORUM identified eight sets of activities to address these issues. They include:

- Creating a successful educational environment for all students;
- Pre-referral problem-solving in the general education arena;
- Referral for special education services;
- Assessment of students in terms of disability condition(s);
- Eligibility for special education services;
- Provision of special education services;
- Home-school-community interaction; and
- Staff development, recruitment and retention.

3. Systemic changes

Two features of the reauthorized IDEA, if implemented, offer the means for fundamental change. First, the law (indeed, this has been the case since 1975) requires that school districts implement "best practices" in student assessment and instruction. Were this done - and the federal government has the authority to see that it is done - the current discriminatory assessment procedure would be ended, as would the inadequate instruction provided to students with disabilities.

Second, the reauthorized IDEA focuses attention on outcomes for students. It asserts that significant outcomes can be achieved when there are "high expectations" for students with disabilities. These expectations are in terms of the regular (not some special) curriculum:

- that the education of students with disabilities in the same classroom as their nondisabled peers is to be the norm and exclusion from such settings must be particularly justified;
- that such education must provide students with disabilities the necessary supplemental aids and support services to enable them to succeed in the general education environment; and
- that the expected outcomes for students with disabilities must be drawn from the outcomes a state expects for students in general and that measures of these outcomes must be incorporated in school and district public reports.

Fundamental, then, is the development of a unitary school system, one where all students learn and succeed together. Currently, students who come to special education are those whom the general education system has failed. They bring this history of failure, and its concomitant depreciations of self and low expectations for success. In a refashioned mainstream, students do not need to be removed to gain the resources needed for success. While we may look to the day when labeling is no longer necessary in order to gain needed services for students - whether they have disabilities or not - a restructured school system where all students are educated well and together is achievable in the context of the current law. As the late Ron Edmonds, who conducted the pioneer research on school effectiveness stated, "The essential problem comes from the structure and attitudes of those in public education today who simply are not overly concerned as to whether minority kids learn."

Alan Gartner is a professor at The Graduate School and University Center, The City University of New York where Dorothy Kerzner Lipsky directs the National Center on Educational Restructuring and Inclusion. Their most recent book is Inclusive Education and School Restructuring (Brookes, 1997). They can be reached at NCERI, CUNY Grad. Center, 33 W. 42 Street, New York City, NY 10036, 212/642-2656.

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INCLUSION ROUNDTABLE

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Rich Villa

If you think of a person and their objection, think that half of their objection is their concerns and half is their beliefs. You will never get a person to change their belief unless they feel you have heard the concern.

You have to listen to that concern and be sure that the kind of information that you are giving them, and the vehicles we use to provide that information, matches what that particular concern is. Like the issue of teachers losing jobs. That was a very big concern from our teachers union. In the end they realize that it is not that people lose their jobs, it's that everybody's job becomes something else.

For some people it is training, for some people it is seeing someone else who is doing it. For somebody else it is trying to figure out what are the incentives. What we are really asking all of these people to do is leave a place where they feel comfortable and perhaps confident and go do something where they feel totally uncomfortable and incompetent until they get a whole new range of skills.

Alan Gartner

There are times when there is a need [to turn to lawsuits]. There are also times when there is a need to state the facts. I don't know every school district in the country, but I do not know of a single school district in which there has been a net reduction in the number of special education teachers as a result of inclusion. People say, which I think is quite a legitimate thing, I do not want to lose my job. Nobody does. There are a set of facts that says that doesn't happen.

Dorothy Lipsky

Parents have to get into more powerful positions. They have to speak up more. People have to run for school boards, get their own degrees and get into those schools and make a difference. They have to vote, and come to school board meetings and really keep up the pressure on school districts to say we are taxpayers and this is what we want and we need.

You speak with the superintendent, you do not take no for an answer, you keep your brief in front of you all the time. Then you go home and you cry and/or talk with a friend. Nonetheless, you keep going. Parents sometimes are really intimidated by the systems and the professionals, but you just keep going.

In systemic change we need all of the stakeholders to be involved. In any community that is going to move forward you are going to have to think about what are the concerns of each group of people. You do have the community, you have the administrators, the staff, the parents, the students. It is very necessary to think about the implementation plan. It should not be that in September the teacher comes in and is faced with a child in the room from a court case. How ridiculous. Schools have to get ready. The law has told us for a long time that there should be monitoring. Nonetheless, every community needs to be thinking about what they are doing to meet the concerns, the barriers that are going to be there to compete with the success, and how to get ready.

Question: *For years we have been told that our kids can't learn, they are not going to learn, so we did not test them. We checked that little box on the IEP that says not to test. We have got to stop that.*

Dorothy Lipsky

Do you understand why the school district wants you to check that box? [School districts'] scores are then way up. With the new law those scores are going to be counted. I am still waiting for regulations to come out so that we get some clarity about how those scores are going to be counted. You have to get out of the thing where parents are in IEPs and marking off [the box] to choose not to have their children assessed.

Phil Ferguson

Dorothy and I have children with similar backgrounds. We have a child also who is 29. Ian had some similar experiences, as well. I will be honest with you, I have mixed feelings about IDEA. My son was excluded by law from attending public school before 92-142 came into being. I certainly appreciate the guarantees and the mandates of the law. Despite the possibilities that open up as a result of the reauthorization, I also confront some of the problems of the ongoing reliance on categorical labeling. The logic underlying IDEA undermines some of the logic we are trying to talk about around inclusive educational practices.

One strand of IDEA has this continuum logic built into it. I find this continuum logic real powerful. This logic that we used with people who are different, in particular people with disabilities, in all domains of life. We have this menu, this array of possibilities from the most segregated to the most integrated. Then what we will do is take the individual and move them along this continuum.

One of the assumptions of the continuum logic is that intensity of support is associated with how restrictive and how sheltered the setting is. If we are talking about moving [a person] into less intensive settings, then we are automatically talking about less intensive supports. I find that not necessarily explicitly stated, but it does underlie the problems that I hear from parents and professionals. We must find a way to isolate that and to challenge that assumption.

Some professionals see it as us asking them to be not just incompetent, but to do something unprofessional. 'When I was trained I was taught to teach triangle kids in the triangle rooms. There are other folks who are trained to teach the square kids and the round kids . Now you are telling me that triangle kids and round kids together? That is not only not what I was told to do, but it is against this continuum where we need to make the perfect match.' We need to work on that as well.

Alan Gartner

I want to pick up on some things people said. Someone said 'It's almost a systems change.' No, it is a systems change and then some. It really does challenge a fundamental set of assumptions. This question of the assessments. As one woman pointed out, we don't expect this child to learn, therefore, you can stay home because tomorrow is the statewide test. Or you can take the test but we won't score it, or we will score it and we won't count it. Well, IDEA '97 says a very different thing about that. It says that

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INCLUSION ROUNDTABLE

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every state has a set of outcome standards for the "real" kids. Kids with disabilities have to have outcome developed for them in the context of outcomes standards for kids in general. Measures have to be developed to assess those outcomes, and the results have to be reported. They have to be reported in two ways:

1. They have to be reported as part of the regular schools' public reporting. The principal who says 'I don't want to have my scores look bad in the paper, because that [school] down the road doesn't do inclusion. I am going to look bad, well now the school down the road has to report, as well. The other thing that the law says is that the reports about the kids' progress has to be made to parents as frequently as it is for kids in general ed in that district. The Congress could have said 3 times a year or 17 times a year, they could have picked an arbitrary number. But they didn't. I think they meant to send us a signal, which is: these are your kids, treat them like you treat the rest. You do [reporting] three times a year, do it three times. You do it weekly, do it weekly.
2. Next point about IDEA, I think there is a very different sense that challenges that continuum in what I call the presumption clause of IDEA. It says you have to have a continuum of services, but it says that in the evaluation and placement decision of a child with a disability, the presumption is that he or she will be served in a inclusive setting with the necessary supports brought there. If the school district intends to place that child in other than the inclusive setting with the necessary supports, they have to justify the violation of the presumption. That is a powerful tool.

Question: *How are they required to justify? Who makes them do that? What information do they have to show?*

Alan Gartner

IDEA makes it a consequence of necessity in every school district to require them, and they'll be sued if they do not. At some point someone is going to say that if you don't do this you are going to be in big trouble. It is the clear intent of the law that says 'Johnny, a 7-year old with this set of impairments, is not to be in the English class with supplemental services because, and [Johnny] cannot be in the science class with supplemental services because...' Subject by subject and area by area is what the law requires. The law is not self-enforcing, but it does require them to put out their however faulty logic. Also, [if they are not complying] find out who your congressman is and how s/he voted on IDEA. I would make it a personal affront to him/her that a school district is choosing to violate a bill that s/he voted for.

Dorothy Lipsky

I would go with other parents to [Congressional representatives'] offices and get the newspaper involved and keep the heat on. Isn't it a sad situation? We have heard from many parents that the school system says we don't want to keep going in this direction. As if they had a choice! They don't have a choice. They do have to keep hearing the pressure and we have to get this information back to Judy Heumann and Tom Hehir because they have to hear these kinds of concerns that we are hearing today. We will, of course, let them know.

Question: *I know we have the law but we need the regulations. In the absence of these regulations the schools are turning to their lawyers to get interpretation and ignoring what the state is saying. Dueling interpretation is a problem.*

Charlene Comstock-Galagan

One of the things you are talking about in terms of keeping the heat on is questioning that continuum logic. A lot of times I hear parents saying 'They say.' I think we need to help parents get really clear that it doesn't matter what they say. It only matters what you continue to say back.

Some good responses back might be:

- How did you come to think that way?
- What evidence do you have to support that?
- Can you show me the information?
- What is your evidence that this placement is not working?

Get a set of phrases and say them over and over. It helps to get them to answer the question. Then you ask, 'Can you please write it down on the paper?' They probably won't do that. So that's the point that Dorothy is making. You have to stay with it. You can never say: 'They said, so we can't.'

Mara Sapon-Shevin

I think one of the things that I am seeing as someone who does a lot of teacher education work around inclusion is that it is really hard for the schools not to see that there are some structural changes that need to be made. What I would like to think is that in the best of all possible worlds, when schools go to include a kid who is very challenging, wouldn't it be nice if the schools would say: 'Thank you so much for sending us Patrick. Before we had Patrick we thought we were doing OK. But Patrick has really illuminated for us all the places we need improvement. Our curriculum needs work, it is not broad, it is not multilevel. Our pedagogy sure needs work because we have been doing all of this frontal teaching and it sure doesn't work for Patrick, so maybe it doesn't work for other kids. The school climate really stinks, there are other kids who don't have friends here, and our teachers really need more support, so thank you so much for sending us this kid.' Not too many places are saying that yet. But there are some places where the reality of that is exactly what has happened. That is where I get hopeful.

We also never paid much attention to our curriculum because it looked like it fit, but it really didn't. One of the things I do with teachers as an opening is I say let's make a list of all of the differences kids bring to the classroom. We quit at about 100 differences. Then we look at the list and say what does it tell us? It is not about disability then, is it?

Those people who thought they had a homogenous classroom before inclusion – where are they? They had all of these differences before, it is just that they were allowed to, by the curriculum and by the school, to act as though they were the same. Inclusion can be this catalyst to say that we better rethink this whole system.

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INCLUSION ROUNDTABLE

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It is not about disability, it is not about special education, it's about curriculum and what kind of children we want to create for the world.

Alan Gartner

What Mara suggests as the 'thank you for Patrick,' I think that is going to happen in two years. Every state now, per Goals 2000, has a set of outcome standards and they are now kicking in. The crisis in New York State is going to come in the year 2001. When lots of the "regular kids" are going to flunk. And there is going to be an uproar. There is going to be a lot of possible responses. One possible response is an enormous increase in the referrals to special education. I think the budget guys are going to block that. Another is to abandon the public schools and go to vouchers. They can't do that. Third is to give up the standards. There is going to be a lot of pressure on the state legislators to do that. A fourth option is that there be a coalescence around this increasingly diverse group of kids, some of whom we have recognized and others who we have not, to meet what we all want which is an improved quality of educational outcome for all youngsters. That is the next step after where we are today.

Question: *How is this changing what is happening for college prep and the reform of teacher certification in that state?*

Jacque Thousand

I am a Vermont transplant, as Rich is to Southern California, which is a huge culture shock. California regulated to Vermont is so segregated in terms of their services to all children. And when I say all, I mean all. But there are some absolutely fabulous things going on in California in terms of some redesign of the credential standards, as well as initiatives to credential the 30,000 teachers who are in classrooms who do not have a teaching credential. There are 30,000 people hired in August who have bachelor degrees to teach.

The first development is our new credential standards and the way in which the universities have responded to them. [They] have restructured almost every program so that we are now dually endorsing our graduates to be general education graduate teachers who at the same time hold a special education credential. In California that is known as Mild/Moderate, and Moderate/Severe. They did not completely eliminate the division, but at least they have the standards that were developed by Marv Falvey and some other colleagues. We have standards that have a solid general education component as well as the special education competencies that I think, although not perfect, this organization would embrace.

In terms of the teachers who are not credentialed, we have looked at the Open University system that comes out of England. We have modeled it where teachers who are in remote areas, for example, would be provided with a curriculum and a mentor so that over the course of 18 months they can develop the competencies to be effective teachers for all. It is a wild project. The chancellor of the 23 university systems convinced the governor to give us 5 million dollars to develop and deliver a curriculum by June. We started in September. Everyone who was nominated and put on the committee has a foundational belief that all means all. Our foundational competencies and activities are going to revolve around: What are instructional strategies? What are collaborative teaming strategies? What are processes for solution finding or problem solving? When do we have a mismatch between what is the California curriculum and the way in which learners show their learning or access education?

What evidence is there that standards- based education actually improves education and that it might lead to more inclusive education?

Alan Gartner

None yet. There is evidence to the contrary. However there is evidence, a good body of evidence, that inclusion leads to improved learning for them as opposed to segregated learning. So in that sense, inclusion works. There are studies which address issues of academic, behavioral and social outcomes for youngsters. There are data that leads one to be reasonably confident about inclusion for both the youngsters with disabilities and those without disabilities.

Mara Sapon-Shevin

One of the hopeful things is that change will happen as Alan said before, that this crisis will cause change. What are they going to say if three-quarters of the population (in the school district) need to be in special education?

Question: *That is exactly what is happening. You are looking at this with a 'glass is half full' attitude. I live in Ohio and they have created intervention classes for kids to pass the proficiency test. They have segregated more.*

Rich Villa

It is a matter of what you set your standard at and how you choose to assess children. Do you teach to the test? A parallel to me is like saying that the solution to malnutrition is to set a higher standard. Saying how much people should eat and what vitamins they should take, instead of looking at the fundamental cause.

Mara Sapon-Shevin

This is a time for political action as far as I am concerned. I think it is mistake to keep talking about this as if it is an education issue and not a political and social justice issue. I think one of the things that has to happen is to broaden the agenda and talk about issues of excellence and equity. To keep going back to this equity thing. How can we say that three-quarters of the kids in our education system are inadequate? This is a time to take to the streets and ask 'What does this mean?'

For more information on IDEA or research on inclusive education, contact Dorothy and Alan at the National Center on Educational Restructuring and Inclusion, 33 West 42nd Street, New York NY 10036-8099; (Phone) 212-642-2656.

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TASH Continues its Vehement Opposition to Washington State's "Reinstitutionalization" Law

TASH continues to oppose the Washington State 1998 Legislature-approved Senate Bill 6751, which allegedly gives people with developmental disabilities "choices" between community services and RHC's (residential habilitation centers).

Not only do we oppose the segregation of people with disabilities in institutions, but we oppose the practice of offering choice on the basis of openings in "slots' controlled by the government. This is not choice.

"This new law states that "to ensure continued choice, both community support services and RHC programs are guaranteed the present level of funding through June 30, 2003. Neither program may be reduced below budgeted capacity unless directed by the Governor. If the Governor directs such a reduction, both community services and RHCs must be considered. If either program experiences a drop in capacity, the vacancies must be used to expand services to eligible people not currently being served. Vacancies in RHCs must first be offered to eligible clients seeking RHC services. If the vacancy can not be filled by a person needing care on a permanent basis, it may be provided

to other families for respite care or other services. These services, however, may only be provided if community support services funding is available. The department will work with the stakeholder group to assess services provided to people with developmental disabilities. Based on this assessment, the group will establish a long-term strategic plan for the department, including phased-in data collection and analysis of programs, services, and funding for people with developmental disabilities." Phase I was set to begin in December 1998.

Taken from the Washington State Republican Caucus Webpage http://www.leg.wa.gov/senate/src/ddchoice2.htm

Please write to the following individuals and to your state Senate and Congressional Leaders to voice your opposition to this bill, and to demand that this type of public policy not continue across the nation.

To find out who your representatives are, contact the Congressional Switchboard at 202-225-3121.

To contact officials in the State of Washington:

Governor Gary Locke
Office of the Governor
PO Box 40002
Olympia, WA 98504-0002
Governor.Locke@Governor.wa.gov

Sen. Dan McDonald (R-48)
Republican Leader
302 Legislative Building
P.O. Box 40482
Olympia, WA 98504-0482
Phone: (360) 786-7694
mcdonald_da@leg.wa.gov

Sen. Pat Hale (R-8)
Republican Caucus Chair
303 Legislative Building
P.O. Box 40482
Olympia, WA 98504-0482
Phone: (360) 786-7614
hale_pa@leg.wa.gov

The Special Education Service Agency - Anchorage, Alaska

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(2) Minimum of three years recent experience with this population;
(3) Qualify for Alaska DOE Special Education Type A (teacher) Certification;
(4) Demonstrated knowledge and skill levels in current "best practices" in the education of students with multiple/significant disabilities;
(5) Current knowledge of assistive technology options for students;
(6) Ability to work collaboratively with team members; and,
(7) Excellent health and the ability to travel extensively and independently in rural/remote Alaska.

Preferred Experience

Direct experience with students with multiple/significant disabilities across age ranges - preschool through high school - and various ability levels; Providing training to professionals and/or paraprofessionals; and Inter-agency networking and collaboration.

Contact: John Lund, Program Administrator — Special Education Service Agency
2217 E. Tudor Road, Suite 1 • Anchorage, AK 99507
(907) 562-7372 • Fax: (907) 562-0545 • e-mail: jlund@sesa.org

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TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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VOLUME 25 ISSUE NUMBER 3 MARCH 1999

From Institutions . . . to Classrooms . . . to the Supreme Court

Closing Brandon Training School

IDEA Regulations Released

High Court To Hear Olmstead

We Are Fighting For Life, Liberty and the Pursuit of Happiness!

ALSO INSIDE:

Do Not Resuscitate-Whose Choice?;
People with Disabilities in Police Interrogation Rooms;
and School District Ordered to Pay for Health Care Services

1999 Calendar of TASH Chapter and Member-Sponsored Conferences

APRIL

15th Annual Arizona TASH Conference
Effective Strategies for Creating Inclusive Classrooms
Guest Speaker: Mary Falvey, Ph D
April 14, 8:30 AM - 3:15 PM
Orange Tree Golf and Conference Resort
Scottsdale, Arizona
Contact: Janet Holt
Phone: 602-661-0650
E-mail: janeth1111@aol.com

Stories of Change: Annual CAL-TASH Statewide Conference
April 22-24
San Diego Marriott-La Jolla, CA
Contact: Eileen Medina,
Phone: 805-967-2042
E-mail: cal-tash@ceo.sbceo.k12.ca.us

The Sun-Tash/Arc Conference
April 22-23
Albuquerque Hilton
Contact: Liz Keefe,
Phone: 505-277-0987
E-mail: lkeefe@unm.edu

MAY

Education in Italy: An Inclusive Approach
May 18-June 9
Site visits to schools in Rome, Florence, Parma and other locations
Contact: Dr. Carol Berrigan, Seminar Director, Syracuse University
Phone: 315-443-3851
E-mail: crberrig@syr.edu

JULY

CAL-TASH Summer Symposiums in Santa Barbara
July 26-27 - "School Inclusion"
July 29-30 – "Positive Behavior Support"
Contact: Eileen Medina,
Phone: 805-967-2042
E-mail: cal-tash@ceo.sbceo.k12.ca.us

1999 Toronto Summer Institute
July 3-9
Toronto, Canada
Contact: Inclusion Press
Phone: 416-658-5363
E-mail: 74640.112@compuserve.com

SEPTEMBER

National Spinal Cord Injury Association
Annual Meeting and Education Conference
September 26-29
Washington, D.C. Marriott - Metro Center
Contact: Denise Marshall
Phone: 410-828-8274, ext. 103
E-mail: dmarsh@tash.org

DECEMBER

Annual TASH International Conference
"TASH 2000 – Our Turn Now"
December 8-11
Chicago Hilton and Towers
Contact: Kelly Nelson
Phone: 410-828-8274 x105 or 1-800-482-8274 x105
E-mail: knelson@tash.org

Do you have an upcoming TASH chapter meeting or member-sponsored conference that you would like to announce in the *Newsletter*? Send notice of the conference to Denise Marshall at dmarsh@tash.org at least 6 weeks before the event date. We will make every effort to include the event in the meeting calendar.

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

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Whom Do I Contact??

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From the Executive Director
BY NANCY WEISS

High Court to Hear Arguments in *Olmstead*

Within the next few weeks the U.S. Supreme Court will hear a case that will affect the rights of people with disabilities as significantly as any case in recent memory. The case, called *Olmstead vs. L.C. and E.W.*, is brought on behalf of two women from Georgia who had to live in a state institution in order to receive the support services they needed. Known by their initials, L.C and E. W. sued the State of Georgia under the Americans with Disabilities Act claiming that being forced to live in a state institution violated their right to services in the most integrated setting. In April, 1998, they won their case in the Northern Georgia U.S. District Court against Tommy Olmstead, Georgia's Human Resources Commissioner. The State appealed, but L.C. and E.W. won again in the 11th Circuit. Georgia appealed the case to the U.S. Supreme Court.

Originally, the Attorneys General of 22 states signed on to an amicus brief, joining Georgia in their effort to keep people with disabilities segregated in institutions. Eventually, six of these states withdrew their support. However, in recent weeks a number of other groups have filed amicus briefs supporting Georgia's claim that by keeping people in institutions, they are not violating their rights as guaranteed under the Americans with Disabilities Act. The groups siding against the right of people with disabilities to receive support outside of institutions include the National Conference of State Legislatures, the Council of State Governments, the National Governor's Association, the National Association of Counties, the U.S. Conference of Mayors, the National League of Cities, The American Health Care Association (the nursing home lobby) and of course, the misnamed, Voice of the Retarded. All but the last of these groups know or care little about the rights of people with disabilities and are concerned only with what a Supreme Court decision in favor of the plaintiffs might cost them. Voice of the Retarded is a parent group that works to keep institutions open.

The Olmstead case is a watershed event. A favorable Supreme Court ruling will mean freedom for hundreds, and perhaps thousands, of people with disabilities across the country. An unfavorable ruling will mean a continued struggle on behalf of each person who remains institutionalized, person by person, facility by facility, state by state. As Justice for All has put it, **"Will Olmstead be our Brown vs. the Board of Education, where school integration was determined to be the right of all children ... or will Olmstead be our Dred Scott, in which the Supreme Court ruled that a slave could not sue for his freedom?"**

You can participate in this historic event and help assure the freedom of people who remain behind walls. The Olmstead case will be heard by the U.S. Supreme Court on Wednesday, April 21st at 10 a.m. Join TASH, ADAPT and disability rights activists from across the country on the steps of the Supreme Court for a candlelight vigil beginning Tuesday, April 20th at 8 p.m. and continuing throughout the night and during the hearing on the 21st. A second rally is planned for May 12th at noon to keep focus on the need to uphold freedom while the justices are deliberating. For more information call Marcie Roth at 410-828-8274, ext. 104, or check our web page: www.tash.org for regularly updated information.

The TASH Elections Committee is seeking nominations for the TASH Executive Board. Nominations and self-nominations are welcome.

Send a letter describing the nominee, his/her past achievements and his/her commitment to TASH. Please provide the name, address and other contact information (phone, fax, and e-mail) for both the person being nominated and the person making the nomination. All nominations received by April 30th will be considered by the Elections Committee in their selection of a slate.

PLEASE SEND THE INFORMATION REQUESTED TO:
Elections Committee c/o Nancy Weiss, TASH,
29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204.

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Letters can also be faxed to Nancy Weiss at 410-828-6706
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Thank You!

We would like to thank Howard Community Services for sharing this graphic for use as the 1999 TASH Conference Logo. The graphic featured is one painting from a trilogy created by the staff of Howard Community Services, a division of the Howard Center for Human Services, in partnership with Vermont artist Suzanne LeGault. Howard Community Services, located in Burlington, Vermont, provides a comprehensive array of supports and services to individuals with developmental disabilities and their families.

For more information on the trilogy contact:
Howard Community Services
Katherine Long
Recruiter, Howard Community Services
109 S. Winooski Ave
Burlington, VT 05401
(802)652-2126

For more information regarding the 1999 TASH Conference contact Kelly Nelson at 410-828-8274 x105 or <knelson@tash.org>

Coordinator, Education/Training Programs
Center for Autism and Related Disabilities
University of Florida

The University of Florida, Center for Autism and Related Disabilities (CARD) has an opening for a Coordinator, Education/Training Programs. CARD is a state funded project that offers support, training, technical assistance, and program development for individuals with autism, sensory impairments with additional disabilities, and deaf-blindness, as well as their families, peers, school personnel, and support providers in the state of Florida. Preference will be given to qualified applicants who have a doctorate or master's degree in special education, psychology, communication disorders, or a related field and direct experience working with individuals with autism and related disabilities and their families.

Salary range is $34,000 to $50,000 depending on experience and qualifications. Minimum qualifications: MA degree in an appropriate area of specialization (Communication Disorders, Psychology, Education, Occupational Therapy, Social Work) or a BA degree in same with 2 years of related professional experience. Experience and/or education in working with individuals who have autism and/or multiple disabilities, including sensory disabilities (hearing, vision or deaf-blindness); experience in working with families; exp. and/or training in adult services; exp. and/or training in inclusion of students with significant disabilities in general education setting; exp. with individuals with significant disabilities who exhibit challenging behavior.

To apply, send cover letter and resume to Diana Stetter, University Personnel Services, PO Box 115002, Gainesville, FL 32611-5002. Reference LP# 60823DS. Current deadline is April 1 but may be extended contingent on response, please call. If an accommodation due to a disability is needed to apply for this position, please call (352) 392-4621 or TDD (352) 392-7734. AA/EA/EEO.

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– Do Not Resuscitate – Whose choice is it?

BY NANCY NOBLE, R.N.

Many people with developmental disabilities living in the communities of British Columbia have had a significant impact on changing preconceived notions about disability. They have pushed the awareness of society in general, and of health practitioners in particular, to higher levels. They have secured health services that are adaptable and individualized, and they have demonstrated that disability is not an ongoing illness. However, although we have seen many gains, there are still areas where people with developmental disabilities are at risk. This article looks at two features of the health care field that continue to place people with disabilities at risk: Do Not Resuscitate (DNR) orders, and decisions to withhold or withdraw nutrition.

The use of DNR orders and advance directives

DNR orders were initially used to ensure that people who were terminally ill or who were facing imminent death were allowed to die with a sense of dignity, in their own time and way, without unwanted and invasive treatment. In recent years, however, questions about resuscitation have been raised well in advance of serious illness in order to determine a person's preferences for how much medical intervention they want at the end of their life. Two vehicles used to formalize resuscitation decisions are living wills and advance directives. Proponents of these vehicles argue that people should document their wishes regarding resuscitation before they face a serious illness or condition that renders them unable to make a decision.

Although ideas and attitudes about serious illness and "incompetence" continue to be redefined by citizens with disabilities, misunderstandings still routinely arise out of preconceived and previously accepted ways of thinking. Within the health care system, practitioners are beginning to make paradigm shifts in thinking about disability and are liberating the definition from a purely biomedical framework. Increasingly, practitioners recognize disability not as an illness but rather as a unique and adaptive human circumstance and lifestyle. However, health care practitioners vary widely in their ability to distinguish between acute illness, chronic illness, and disability. It is precisely this confusion that influences and defines decisions about resuscitation, and judgements about whether or not it is "futile" to provide treatment.

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In many cases one can interpret conclusions about "poor quality of life" as indications of a failure in service delivery, as a signal of the need to reconsider how the person is served rather than a need to restrict treatments or resuscitation.

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The difficulty of distinguishing between disability and illness is complicated by another factor: assessing quality of life. Health professionals have concerns about providing treatments that may ultimately be more harmful than beneficial. They see quality of life issues as a way to safeguard the patient from being increasingly incapacitated as a result of treatment. The challenge here is that making quality of life decisions for others involves subjective judgements; assessments of quality of life are coloured by societal bias and by the practitioner's experiences and knowledge about disability. As a health practitioner's focus shifts from assessing clinical factors to assessing the impact of a person's level of disability, the judgements of "poor quality of life" becomes greater. The assumption is if you have a disability, you don't enjoy life. Conclusions of this nature then justify non-treatment decisions.

In many cases one can interpret conclusions about "poor quality of life" as indications of a failure in service delivery, as a signal of the need to reconsider how the person is served rather than a need to restrict treatments or resuscitation. There are examples in the disability community of people who were in crisis when they lived in an institution, yet they thrived when they moved into the community. Similarly, there are individuals who experience poor quality of life in one type of living arrangement yet thrive in a life-sharing model of support.

Several factors influence how advance directives and resuscitation decisions are made. Predictions about life expectancy and "mental age" can play a significant role in such decisions. For example, if a person has already surpassed the predicted life expectancy associated with their disability and they develop a serious acute illness, they may be considered to be at the natural end of their life and not be offered full treatment. Yet, estimates of life expectancy may be based on old information that has not been reviewed or adapted to the individual's current situation. Similarly, decades ago, people with developmental disabilities were sometimes assigned a "mental age" without consideration of how future life experience and psychological, social and spiritual development would alter and change them.

People with or without disabilities often raise another important question about resuscitation and advance directives. How can a patient's response in a medical crisis or the outcome of a treatment for that crisis be accurately predicted? It is difficult to predict with certainty how an individual will respond, what complications will or will not arise, and what interactions with other co-existing traumas or treatments will occur.

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– Do Not Resuscitate – Whose choice is it?

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It is predictable, however, that patients will have a chance of survival, a chance to face their trauma and treatment outcomes, if they are resuscitated. Unfortunately, advance directives cannot always offer a safeguard. They cannot anticipate every possible scenario, nor can they allow for a change of mind or circumstance in all cases.

Another factor that often guides decisions about resuscitation is whether the person's condition or quality of life is likely to improve as a result of the intervention. When the person has a pre-existing disability, one has to wonder to what extent a decision about whether or not to resuscitate is determined by the realization that a life-sustaining intervention will not "improve" or change the disability.

Frequently, tools for assessing quality of life and competence do not allow for the consideration of unique circumstances, personal diversity, cultural expectations, environmental expectations, and differing values. Using generic tools developed for systematic efficiency will not accurately evaluate, for example, the competence or quality of life of those with developmental challenges, hearing impairment, mental illness, or those who communicate non-verbally or speak a first language other than English. Standard generic tools may result in false conclusions of incompetence, poor quality of life, lack of awareness, distress, and/or lack of positive experiences.

Advance directives and DNR orders operate within an institutional culture, and to some extent they represent the need to bring some level of organization and efficiency to the task of providing health care to large populations of people. At times such organization may be useful in providing direction to practitioners as to the wishes of the individual when treatment decisions are necessary.

However, if the basis of understanding at the root of compiling information and the process that goes into establishing advance directives are flawed, then people can find themselves facing compromised non-treatment decisions. Furthermore, it is not always possible for people with disabilities to use whatever procedures have been put in place to change or appeal decisions. One of the best safeguards for individuals to avoid such risks is to appoint a few selected loved ones who can assist with making decisions about treatments and resuscitation should they become unable to do so themselves.

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Quality of life judgements in this context present similar problems for people with disabilities as they do in relation to resuscitation decisions — quality of life is a subjective assessment, coloured by the experience, values, and biased measuring tools of the health practitioner.

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Fortunately, many people are gaining an understanding of the multifaceted and high-risk nature of resuscitation and treatment decisions for people with disabilities. Within hospitals, diversity programs are striving to honour and understand the ways in which disability has far-reaching implications for service delivery, and patient-centered care initiatives are focusing on individualized services.

In addition, some ethics committees will review decisions that are made on behalf of an individual. The power of an independent second opinion has proven most effective to help determine if an individual has had the benefit of thoughtful, personalized treatment options. Personal advocacy and medical advocacy have also on occasion proven to be necessary and beneficial.

Withdrawing and Withholding Nutrition

Recently, hospitals and family practice physicians have considered draft guidelines to define the delivery of food and fluids as a treatment. This means that nutrition would be subject to a decision-making process about whether or not to withhold or withdraw it as a treatment. The draft guidelines propose that health practitioners use measurements of quality of life to determine whether or not to provide food and fluids. Quality of life is measured in this instance by assessing awareness, distress level, and positive experiences. It appears that under these guidelines, physicians would ultimately decide, on the basis of "futility" or "non-futility," whether or not to provide treatment.

Quality of life judgements in this context present similar problems for people with disabilities as they do in relation to resuscitation decisions — quality of life is a subjective assessment, coloured by the experience, values, and biased measuring tools of the health practitioner. For example, many people in their homes may eat with the aid of gastronomy or jejunostomy tubes. Outside of a hospital, this is their "norm," it is part of their adaptive lifestyle. In the context of an acute care hospital, however, tube feeding is perceived to be a treatment.

Although there may well be instances in the dying process when it seems ethical and clinically sound to stop nutrition or not to force nutrition, the potential for misguided decision-making about the lives of people with disabilities is extremely high. The Euthanasia Prevention Coalition of British Columbia is increasingly concerned about the impact of the slippery slope toward physician-assisted suicide and euthanasia on the lives of people with disabilities. The Coalition has responded to the draft guidelines for the delivery of food and fluids from this perspective.

Health care practitioners, and indeed society at large, continue to gain an understanding of the ways in which we contribute to inequitable treatment for people with disabilities. Yet, health care practitioners, families, and advocates may vary widely in their ability to challenge health care institutions on behalf of the individual.

Without a deeper understanding of how we perceive disability, and some evolution in how we judge the quality of life of individuals with a diversity of abilities, policy guidelines about resuscitation and the delivery of food and fluids threaten to open the door to more dangers than benefits.

Community Living News, Fall/Winter 1998. Reprinted with permission of the author. Nancy Noble is a health care practitioner who currently sits on the Board of Directors of the Euthanasia Prevention Coalition of British Columbia. For more information, please contact Dr. Will Johnston, Co-Chair of the Coalition, at (604) 324-4155; or Dr. Toni Parsons at (604) 986-0543.

CLOSING BRANDON TRAINING SCHOOL: A VERMONT STORY

BY BONNIE SHOULTZ, PAM WALKER, KATHY HULGIN, ROBERT BOGDAN, STEVE TAYLOR AND CHARLES MOSELEY

The Brandon Training School (BTS), Vermont's only public institution for people with mental retardation and developmental disabilities, opened in 1915 and closed in 1993. During those years, a total of 2,324 people lived there. This article examines the closure process for Brandon; it is based on a larger report of a study conducted by the Center on Human Policy.

The Idea of Closure

The values of a community or group of people permeate and influence what they do, including how their service systems operate. People in Vermont felt that shared values such as "caring for one's neighbors" and "those who have the least deserve more" helped create a consensus in support of closure. Additionally, people felt that Vermont's small size facilitated the communication and collaboration involved in closure.

Closing Brandon took approximately 20 years. Vermonters who have been connected to the developmental disability service system for 20 years or more trace the idea of closing BTS back at least to the mid-1970s. In those days, more people were leaving BTS than entering and the census had gone down, dropping from nearly 700 in 1968 to around 450 in 1976. A few key people attended workshops conducted by Wolf Wolfensberger and his colleagues, adopted normalization as a philosophy that should be applied in Vermont, and talked about developing a broader range of community services. The idea that BTS should be closed was raised and became a part of their overall mission. Those leaders began to develop some of the pieces that were later seen as crucial strategies that led to closure.

The Vermont Association for Retarded Citizens (now the Arc), the state, and the Developmental Disability Law Project worked to establish legislative bills and executive orders that helped to build the community service system. Another major event during those years was the filing of a lawsuit by the Vermont Developmental Disability Law Project (protection and advocacy agency) on behalf of Robert Brace and five other residents who wanted to move into the community. The settlement in 1980 of this lawsuit, called the "Brace Decree," included a 10-year plan for developing community resources and moving most of the approximately 300 residents out of Brandon. Although the settlement did not mention closure, according to one of the lawyers, "we knew that if in fact they carried out the terms of the settlement...they were going to end up with three people in the place," and it would have to close.

Nearly 250 people moved into the community between 1979 and the early 1980s, due in part to the state's successful application for and use of the Medicaid Home and Community Based Services Waiver. Later, community placement dropped as resources and political support for movement dwindled. By 1988, when a new director of the Division of Mental Retardation was appointed, the average daily number of residents in Brandon was nearly the same as in 1982. Division staff came to believe that many statewide problems could be traced to the continued existence of Brandon.

In Vermont, as elsewhere, a community of advocates—parents, attorneys, professionals, and caring citizens—had a dramatic effect on the shape of services and on the eventual closure. One said,

> *"It's not like we sat down 20 years ago and said, 'How are we going to do this?' We really built our philosophy and our mission. We built up the community by demonstrating that success could be achieved. That's the biggest teacher, I think, more than just words."*

The philosophy and the mission were based on a simple ethic: that in Vermont, everyone should be in the community. That ethic was first carried out in the school systems across the state, which are among the most inclusive of any state in the country.

The judicial review process was used for at least 15 years, and the finding almost always was that the person should leave the institution. One attorney reflected, "I think one of the things about Vermont that is different is that our project worked a lot of the time hand-in-hand with the Division of Mental Retardation." People seemed to see them [the Division of Mental Retardation] almost as allies rather than adversaries because both had the interest of the residents — and the need to move them into the community — in mind.

Beginning the Closure Process

In 1988 following the appointment of a new Division director, closure planning actively began. The following year, the director distributed a "Unification Plan," which outlined the problems and a solution: unifying the system by closing Brandon and converting to a fully community-based system. The Unification Plan had three major objectives: (1) to convert the system of services from a two-tiered structure supporting both the institution and the community, to a unified community-based system; (2) to move all remaining residents of BTS to the community; and (3) to build the capacity of the community mental retardation system to respond to special education graduates, families in need of in-home support, young adults aging out of social services custody, persons with mental illness and mental retardation, persons with mental retardation who commit crimes, and persons in crisis.

Once the Governor's office, the legislature, the vendors, and the advocates had agreed that Brandon should be closed, many pieces had to be put in place. Until Brandon closed, bridge money had to be allocated so that both the institution and the community services could operate as effectively as possible, and so that new community programs and an infrastructure could be developed. The needs of the

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state workers who would lose their jobs had to be addressed, and the community providers had to develop the programs and infrastructure that would allow them to serve both the residents of Brandon and people waiting for services. Financial issues such as the fact that Medicaid reimbursement rates would be lower for community services than for Brandon, and the need to develop an individual budgeting mechanism had to be dealt with as well.

While the Unification Plan had stated that it could be done, not everyone agreed at first on how to do it. The Division planned to move ahead, selecting those agencies that were willing to work with them from the start. If need be, they were prepared to develop additional agencies to assist in this process. However, the existing providers came together and developed an implementation plan showing how they could work to make closure and expansion of community services occur in a concrete and timely way.

One theme that came up repeatedly was that what was good for the residents of Brandon Training School had to be the starting place for decision-making. This belief was shared by people from almost all of the stakeholder groups. The only people who opposed closure also used "the good of the residents" as their reason. These stakeholders included some members of the Brandon Training School Association, many of the employees at Brandon, and some of the Brandon townspeople (many of whom were also employees or families of employees). It was evident by 1990, however, that BTS could and would close, and that the major stakeholders would be able to work together to make it happen.

Division's Role in Closure

The Division developed and followed through with many structural changes that made closure possible. They developed an individualized budgeting approach to funding community services, using the Medicaid waiver. They created an infrastructure that would support closure, working actively with the providers and developing or funding what they felt they would need to carry out the plan. For example, the providers felt strongly that they needed a backup system to handle crises, especially those involving behavior that was dangerous to an individual or the people around him or her. The Vermont Crisis Network was developed to respond to this need.

The Division also developed criteria regarding where and how people could be placed in the community. One criterion was that, whenever possible, people should live close to their friends and families, and that family members and/or guardians would be as involved as much as possible in the planning and placement decisions. The Division also empowered Brandon staff members to have input into placement decisions.

Division staff met monthly with all of the community agency directors. During these meetings they received commitments to serve each person who was supposed to move during that month. Because the money they had to spend was to come from money saved through the closure process, they transferred funds at different times, with the transfers tied to the layoffs that occurred as the dorms were emptied. The bridge money they were allocated, $400,000 a year for two years, gave them the ability to support a person in the community before the layoff of staff in the institution could be completed.

The central coordinating function carried out by Division staff members was critical to the success of the closure process. In addition to orchestrating the timing and the numbers of placement, they followed up on problems along the way and worked closely with the institution director and his staff.

Finally, the Division did a great deal to support the BTS staff in getting other jobs. The Department of Employment and Training opened an office on campus. They also had job fairs, and made resume books that people could look through. The Agency of Human Services, at the Division's request, granted a special priority for people coming from BTS for new state job openings.

Community Providers' Response: Service Planning and Development

Community services in Vermont are provided primarily through nine community mental health centers, which provide both mental health and mental retardation/developmental disabilities services. Years ago, the directors of the services for people with mental retardation and developmental disabilities formed their own organization, the Vermont Mental Retardation Program Directors. This organization, and the individual directors, played a major role in the closure of BTS, the development of individualized services, and the creation of safeguards. As they worked on these issues, they benefited from the accessibility and collaboration of state and regional administrators.

Moving toward individualized services. As was to be expected in the deinstitutionalization process, certain pressures influenced the effort to develop individualized services. For example, the decision of where residents of BTS moved was somewhat determined by the capacity of the different agencies. Other pressures, such as the commitment to employ staff of BTS and to serve a large number of people in a short period of time, influenced the development of services, as well.

Though they realized that some group living situations would have to be developed in the interest of time, directors as well as state administrators agreed to develop only a very limited number of agency-operated facilities. Instead, they relied on a service model called the "developmental home" to serve the largest group of people. This typically consists of a person or family who agrees to share their home with an individual and support him or her. Funding levels are determined on an individual basis by the agency that is developing services. In many of these situations, it is a staff person from BTS who has invited an individual to live in his or her home.

Directors are aware that some of these situations may not be the most ideal or individualized possible. In any institution closure process, such trade-offs inevitably occur in the interest of timely closure. At the same time, the fact that they have acknowledged the trade-offs, and have not created a vast number of group living situations will facilitate the future development of individualized services. In addition, the directors' efforts to create and maintain responsive agencies by keeping agency size small and supporting staff enhances their capacity to develop further individualized supports.

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Creating safeguards. During the closure process, Vermont's capacity to support people in crisis situations in the community was strengthened through the establishment of a statewide crisis network, as well as the development of expertise at local levels. Though the Vermont Crisis Network offers emergency placement in some cases, it was developed primarily as a system to build the capacity of agencies around the state to support people in crisis. From the beginning, there was a strong belief that service providers must maintain primary responsibility and enable people to stay in their homes regardless of problems they may have. There are three levels of services provided through the network: (1) interested members of agencies throughout the state participate in monthly meetings to present challenges and problem solve together; (2) members of the network are available to visit an individual, his or her family, and the agency providing services to assist them in developing a plan for change; and (3) in situations where a person is considered at risk, the network provides emergency, temporary placement, while the agency is involved in developing the capacity to support the person.

Conclusion: Key Factors Related to Closure

1. *Recognition of shared values and common vision.* It was significant that shared values and a common vision were held and recognized across a variety of groups of people within the state, including many parents, people with disabilities, state administrators, agency administrators, and advocates. This, in turn, influenced other key groups, such as union representatives, legislators, and Brandon community members, many of whom adopted and added to the vision.
2. *Long-term efforts of advocates in building a consensus.* The shared values did not just naturally emerge. They were the result of years of work by advocates to build a common vision through education, training, litigation, judicial oversight, and personal networking.
3. *Accessibility of state administrators.* Many people reported that the accessibility of state administrators facilitated the work toward closure. They seemed to be knowledgeable about what was going on at the local level, and people felt comfortable walking into their offices and talking with them.
4. *Responsiveness of administrators.* It seemed to people that administrators made every effort to be responsive. They took time to listen to people's issues, and they made sincere efforts to respond in some way to these issues.
5. *Good communication and trust between people.* The fact that there was good, open communication between a wide variety of individuals and constituencies facilitated the closure process. People could disagree and debate issues without feeling that their relationships would be jeopardized.
6. *Focus on building the capacity of the community.* Rather than focus on the closure of Brandon alone, emphasis was placed on expanding and strengthening the community service system. Resources were allocated to the community service system to support this effort.
7. *Significant and careful planning.* State administrators and community service providers devoted considerable time and effort to planning for the closure of Brandon and expansion of the community service system. The planning process attempted to anticipate needs and to put structures in place to deal with potential challenges. Planning also encompassed alternative employment options for BTS staff. While closure did cause some difficulties for employees, the large majority were offered reasonably comparable positions.
8. *Collaboration among community service providers.* Rather than competition between service providers, there was significant collaboration among them. Together, they reached consensus about supporting closure, and planned and strategized ways to best serve people in the community by building on existing strengths of providers and working to fill in gaps in the service system.
9. *Development of a positive working relationship with the local community around issues of closure.* The closure of BTS presented some hardships on the Brandon community. It was positive that state administrators worked collaboratively with Brandon community members to deal with issues, particularly regarding alternative uses for the facility.
10. *Maximizing the opportunities for development of individualized supports at the time of closure and in the near future.* Finally, as people moved out of Brandon, efforts were made to assist as many people as possible to move to individualized settings of their choice. However, as in any process of institutional closure, it was not feasible to create individualized settings for a large number of people in a relatively short period of time. In light of this, however, the state made little use of group homes and other facilities, and relied more extensively on placement in developmental homes. This seemed to be a reasonable compromise, one that is preferable to group homes and one that will create less obstacles to future development of individualized supports.

The experience of closure of BTS has demonstrated both the possibilities for institutional closure, as well as the possibilities for operation of an entirely community-based service system. While the task of closure and conversion to a community-based system was on a much smaller scale in Vermont than in most other states, the experiences nevertheless provide valuable strategies and lessons for those elsewhere interested in working toward closure.

This article is based on a longer report: Shoultz, B., Walker, P., Hulgin, K., Bogdan, B., Taylor, S., & Moseley, C. (1999). Closing Brandon Training School: A Vermont Story. Syracuse, NY: Center on Human Policy. For copies, please contact the Center on Human Policy at 315-443-3851 or e-mail <The CHP@sued.syr.edu>

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Portrait of an Artist

BY LARRY BISSONNETTE AND PASCAL CRAVEDI-CHENG

Larry Bissonnette

Uncle Leo's Earthy Dwelling (1989)

Larry Bissonnette is an artist who lives in Winooski, Vermont. Larry spent over ten years living in Vermont's state institution for people with developmental disabilities, Brandon Training School. His experiences there have provided the subject matter for many of his paintings and drawings.

Maddening Crowds Lessen Where Pods of Slackered Paint Kick Into Gear (1996)

In 1991, Larry was introduced to facilitated communication (FC), which helped him to combine words with his art to express his thoughts and ideas.

Utterly Grey Day at Brandon Training School (1988)

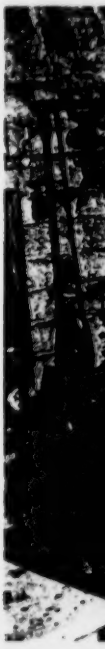
Motion Sensitive Lounging Viewers of Movies Clammer Noisily for First run Rolls of Adventure Rather Than Reruns of Oklahomaed and Worn Out by Nonstop Projections (1996)

Continued on page 12

Larry has been actively involved in educating others about FC and the importance of self-expression for people with disabilities. He presents regularly to college classes and community groups, and at local and national conferences.

Pell

(Left) Aunt Theresa



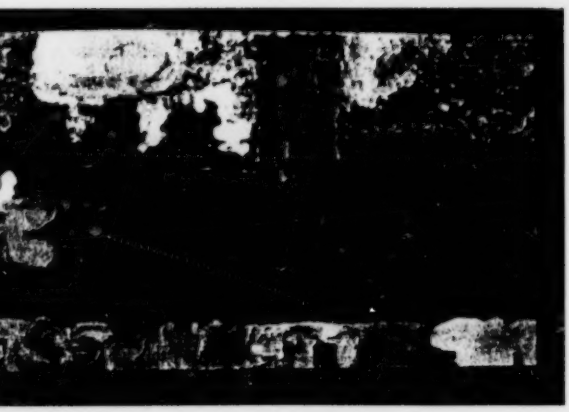
Larry has been drawing and painting since he was a young child. He is one of the featured artists of the GRACE Project (Grass Roots Art And Community Effort) based in Hardwick, Vermont. Larry's work has been exhibited both locally and nationally and, most recently, as part of the GRACE exhibit at the annual Outsider Art Fair in New York City in January 1999.

Larry welcomes inquiries about his art. His address is 93 Pine Stre
you may do so in care of Pascal Cravedi-Cheng at pascalcc@howa

Pell Mell Mainland of Rolling Fortress of Monastery of Brandon Training School (1987)

(Left) Aunt Theresa Rings in Her Eyes Pizzaz (1987)

Larry at work in his studio.



My Muralistic Sensitive View of Life (1996)

ss is 93 Pine Street, Winooski, Vermont 05404. If you wish to contact Larry by e-mail, pascalcc@howardcenter.org

The Utter Vulnerability of Persons With Mental Disabilities In Police Interrogation Rooms

by Robert Perske

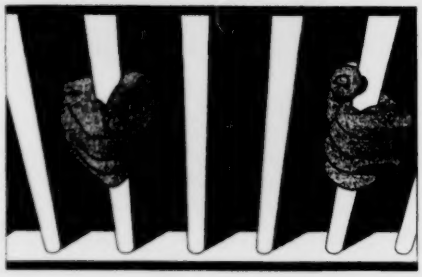
Author's Note: At the National Conference on Wrongful Convictions and the Death Penalty (Northwestern University School of Law, Chicago, Illinois, November 13-15, 1998), 75 innocent people who had been wrongly sentenced to death were invited to attend. Twenty-nine made the engagement and their speaking for themselves made the conference a momentous experience. Others were not yet ready to participate in such a large meeting. Nevertheless, a number of lawyers, academics and advocates were invited to speak on behalf of all those who had been exonerated. One of those presentations follows.

My circle of competence is small. I'm a worker and writer who tracks persons with retardation and other mental disabilities who were coerced into confessing to heinous crimes with little or no physical evidence to back up their admissions. I began this pursuit some 20 years ago because of a murder conviction in a town where I used to live.

On a warm spring night, just after supper, two detectives appeared at the home of Sammy Rafter, 20, a man with mental disabilities. They asked Sammy if he would help them solve a crime. Sammy was thrilled. His folks were puzzled, but they let him go to the police station.

Sammy was taken to an interrogation room in an isolated area, far in the back of the station. He didn't come out until early the next morning—after he had signed a confession for the murder of 13 year-old Jonathan Brooks. Later, he was convicted even though no physical evidence tied him to the crime (Perske, 1991). Five things about this case continue to haunt me today:

- I'm haunted by the first thing Sammy said to his dad after coming out of the interrogation room: "Dad, you'll be proud of me. I helped them solve the case."
- I'm haunted by a tape recording of the interrogation that kept going on and off. The detectives were vague about its malfunction. (Many tape recorders seem to go on and off like this in interrogation rooms.)
- I'm haunted by Sammy's corrections of misspelled words in the confession that had been written out by a policeman. Certain words were crossed out and corrected and initialed by Sammy—even though he didn't read and write very well, let alone edit. (This happens over and over again with vulnerable persons.)
- I'm haunted by one thing a detective said when the tape recorder was working: "Sammy, come on. Tell us, Sammy. Sammy, can't you say it? Sammy, you're my hero. Tell us how it went."
- I'm mostly haunted by the swearing contest between the family and the interrogators during the trial. The family swore on the witness stand that Sammy was home with them when the crime was committed. The interrogators, on the other hand, testified that "Mr. Rafter told us things that only the killer could know." (This exact statement is voiced often by interrogators, especially when there is no written or electronic recording of what actually happened in the interrogation room.)



Sammy in his trusting way was no match for his interrogators. They were well trained in the use of deceptive tactics—all aimed at getting a confession for murder out of Sammy. If a cunning predator like Ted Bundy had been the suspect, the detectives would have certainly treated him differently. But Sammy was a sitting duck. If he had committed the crime, the confession would come easily in that coercive setting. If he didn't do it, a confession would still come easily.

Why? Because Sammy possessed certain propensities that interrogators used against him. Nine of these follow that come from a longer list we should know about (Perske 1991, pp. 15-23).

1. <u>Relying on authority figures to solve tough problems</u>. Many of us get zest out of life by spending days solving tough problems. Some of us, however, survive by listening for answers from people in power. That's why one innocent man, when put under pressure by an interrogator, finally said, "If the evidence shows that I was there, and that I killed her, then I killed her. But I don't remember being there."
2. <u>Pleasing powerful people as a means to remove the pressure</u>. An excerpt from an intermittent tape recording of Johnny Lee Wilson's four-hour interrogation:

Interrogator: "I told you it's important that you be straight with me. You took the the tape up there [meaning the duct tape used on the murder victim]."

Johnny: "Huh?"

Interrogator: "You took the tape up there."

Johnny: "I didn't have anything with me."

Interrogator (shouting): "WE HAVE GOT TO GET THE TRUTH OUT. ONLY THE TRUTH. WHERE DID YOU GET THE TAPE? DID YOU GET IT AT SCHOOL, OR DID YOU GET IT AT HOME, OR DID YOU BUY IT AT THE STORE? WHICH ONE OF THOSE?"

Johnny (sheepishly): "I had it at home." (Sonneborn, 1995).

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The Utter Vulnerability of Persons With Mental Disabilities In Police Interrogation Rooms

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3. Concrete thinking. "Why did you waive your Miranda rights?" has been asked of many who unwittingly did so. The most usual answer: "Because in the police station, you always wave at the right. You don't wave at the wrong." For many, the deeper meaning of Miranda is just too abstract for them to catch.
4. Watching for clues pointing to the right answer. One can find transcript after transcript where all of the yes-and-no answers were influenced by the way the interrogator posed them. An excerpt from one of them:

Question: **You did see John before he died, didn't you?**
Answer: **Yes.**
Question: **Your family said your were with them.**
Answer: **Yes.**
Question: **You couldn't have been with both of them? Which is it?(Silence)**
Question: **Were you with your family or were you with John?**
Answer: **With John.**
Question: **Let's run that one by again, were you with John or were you with your family?**
Answer: **Family.**

(Sonneborn, 1995, p. 17)

This man worked so hard to give the answers the interrogator wanted he gave up thinking about what he was actually saying.

5. Bluffing greater competence than one possesses. The interrogators testified that Johnny Paul Penry sounded competent to them. Even so, when defense attorney John Wright put him on the stand and questioned him, the court learned that he couldn't read or write. He couldn't say how many nickels were in a dime.When asked who was president, he smiled knowingly and said, "Nixon," even though it was the last year of Jimmy Carter's administration (Ellis & Rice, 1988).
6. An all-too-pleasant facade. Herbert Welcome's smiles helped to get him convicted. The interrogators claimed he did it because he lacked remorse. On the other hand, defense attorney Judith Menadue stated: "Many people with mental retardation smile a lot. But this is related to retardation and not remorse. They are anxious for approval, and have learned that smiling is one way to get approval. But they don't have the judgment to know when to smile." (Zehr, 1991).
7. A quickness for taking blame. Some of us are unable to understand when certain behaviors are blameworthy and when they are not. Sammy Rafter thought that if he took the blame for the murder of Jonathan Brooks, the police interrogators would like him.
8. Impaired Judgment. One prisoner used to walk up to police officers repeatedly and ask if they had solved the murder of one of his relatives. Then, since he liked talking to officers, he asked if he was a suspect. That behavior got him a trip to the interrogation room where they coerced a false confession out of him. A citizens group is now into its eighth year trying to show the he couldn't even begin to commit the crime for which he was convicted.
9. Short attention span and uncontrolled impulses. During Johnny Paul Penry's trial, the prosecutor pointed at him and shouted that he was "not just a sociopath." He was worse than that. He was "a vicious psychopath!" That would be enough to get most defendants grasping the defense counsel table until their knuckles became white. Not Johnny. In spite of the prosecutor's angry outburst, Johnny turned to watch a woman having a coughing fit in the audience.

Propensities like these force one to look deeper at the fairness of getting confessions from people with mental disabilities and to draw some fresh conclusions:

➤ **The Miranda warning does not necessarily protect persons with mental disabilities.**

For most of the people we work with, the Miranda warning is only a speed bump. "You have a right to a lawyer." (People who are being interrogated might think: I don't need a lawyer. I didn't do anything.) "You have a right to be silent." (I'll talk. I don't have anything to hide.) "Will you sign this waiver of your rights?" (Sure. in special ed, I was taught that policemen are my friends). After the person signs the waiver sheet, the trap door snaps shut.

➤ **Miranda rules do not necessarily stop terrorism in the interrogation room.**

They do put an end to physical violence. But the psychological terrorism that often takes its place can be more devastating to the people we work with than the physical stuff.

➤ **There is a difference between the honesty exhibited in the interrogation room and the courtroom.**

In the police station, in-your-face lying is an acceptable tool for getting a confession. In the courtroom, every person testifying must swear to tell the truth, the whole truth, and nothing but the truth. The hardened criminal sees through the expected deception in the police station, but the people we work with often do not.

➤ **Fair interrogations happen best in front of nonstop television cameras.**

This means the sound and visual components are turned on when the suspect enters the room and the recording continues until the suspect leaves. Then, and only then, can a judge and jury get a reasonable glimpse of what actually went on in the interrogation room. It doesn't mean turning the video camera off to get some things "corrected," then turning it on again.

➤ **There is a primitive urge in all of us to kill scapegoats.**

Most of us feel it and control it. The urge was present in 1693 Salem Village. In the minds of the Puritans, their community had become a vicious battleground between God and the Devil. So in an effort to cleanse the community, 20 of the Devil's witches were killed.

In 1694, many more were on their way to the gallows, but people began to come to their senses. The cases against 49 other accused witches suddenly melted like butter on a hot summer day. It happened because "spectral evidence" was eliminated. That

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The Utter Vulnerability of Persons With Mental Disabilities In Police Interrogation Rooms

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meant that hysterical young maidens could no longer get others hung by saying they saw them flying through the air.

Even so, Chief Justice William Stoughton was still filled to overflowing with the need to cleanse the community by killing folk. So he signed the death warrants for Elizabeth Johnson, Mary Post and Elizabeth Wardwell.

Why? Because these three women were "feebleminded." They had not been convicted by "spectral evidence." They were picked out of the crowd as being slow. They were merely arrested and questioned until they confessed to being witches (Hill, 1995, Starkey, 1949)

So when today's criminal justice system fails to recognize the irrational urge to cleanse itself or its community by killing—if they fail to take into account this urge and harness it—watch out for what can happen in interrogation rooms.

It might be hard for them to confront, question and get a confession from the governor of Illinois or the quarterback for the Chicago Bears. But God help all of the vulnerable people who may get taken into that room.

Robert Perske is an author and prison worker. He can be reached at 203-655-4135.

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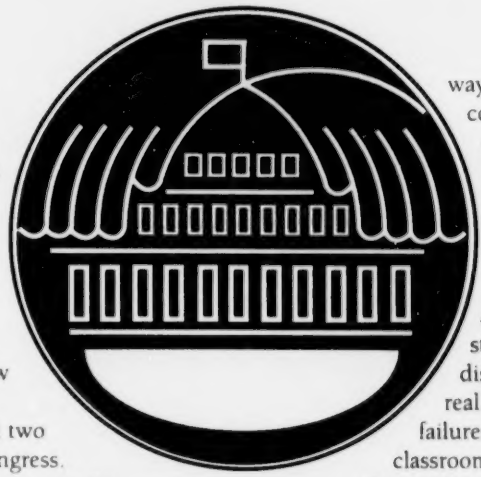
IDEA Regs Released

BY MARCIE ROTH, DIRECTOR OF GOVERNMENTAL AFFAIRS AND PUBLIC POLICY, TASH



On June 4, 1997, President Clinton signed the Americans with Disabilities Education Act of 1997 (IDEA) into law. The need to make changes in the 23-year-old law had been hotly debated for almost two full sessions of Congress. The final product was seen by many to be nothing more than another opportunity to delay the long overdue work necessary to get the law implemented and enforced in America's classrooms, because the changes would now require a rewrite of the regulations governing the new law. For many, this meant that the focus would continue to be on everything but the delivery of a quality education for every child.

When the proposed regulations for implementation of IDEA were published almost 18 months ago, over 6,000 comments were submitted to the US Department of Education, Office for Special Education and Rehabilitative Services for consideration in drafting the final regulations.

When the public comment period ended, a period of waiting ensued. During this waiting period, a number of bills and amendments were proposed by members of Congress that would further change the law (and result in a need for additional rewrites to the pending regulations). There was a flurry of activity at the end of the 105th Congress, and one particular amendment was written into a study by the Government Accounting Office (GAO). This amendment discusses the impact of the dangerous and disruptive behavior of students with disabilities in America's classrooms. That study is now underway, and there is concern that the questions to be answered are posed in such a way as to get answers that will further fuel the arguments that students with disabilities are the real cause of the failures in America's classrooms.

The final regulations for educating all children with disabilities were published in the Federal Register on March 12, 1999. There are sections in the publication which cover: Effective Dates of Regulations; Major Changes in the Regulations by Category, including Free Appropriate Public Education, IEPs, Services to Children in Private Schools; Procedural Safeguards, including signficant changes in due process, evaluations and eligibility; Discipline; and Frequently Asked Questions About Discipline Under IDEA.

* * * * * *

One of the notable highlights includes language on Least Restrictive Environment, including the following statement of particular interest.

Least Restrictive Environment (LRE) Sec. 300.550 General LRE requirements.

(a) Except as provided in Sec. 300.311(b) and (c), a State shall demonstrate to the satisfaction of the Secretary that the State has in effect policies and procedures to ensure that it meets the requirements of Secs. 300.550-300.556.

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IDEA Regs Released

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(b) Each public agency shall ensure—

(1) That to the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are nondisabled; and

(2) That special classes, separate schooling or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily (Authority: 20 U.S.C. 1412(a)(5))

Sec. 300.551 Continuum of alternative placements.

(a) Each public agency shall ensure that a continuum of alternative placements is available to meet the needs of children with disabilities for special education and related services.

(b) The continuum required in paragraph (a) of this section must—

(1) Include the alternative placements listed in the definition of special education under Sec. 300.26 (instruction in regular classes, special classes, special schools, home instruction, and instruction in hospitals and institutions); and

(2) Make provision for supplementary services (such as resource room or itinerant instruction) to be provided in conjunction with regular class placement. (Authority: 20 U.S.C. 1412(a)(5))

Sec. 300.552 Placements.

In determining the educational placement of a child with a disability, including a preschool child with a disability, each public agency shall ensure that—

(a) The placement decision—

(1) Is made by a group of persons, including the parents, and other persons knowledgeable about the child, the meaning of the evaluation data, and the placement options; and

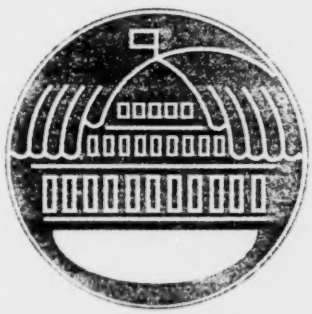
(2) Is made in conformity with the LRE provisions of this subpart, including Secs. 300.550-300.554;

(b) The child's placement—
(1) Is determined at least annually;
(2) Is based on the child's IEP; and
(3) Is as close as possible to the child's home;

(c) Unless the IEP of a child with a disability requires some other arrangement, the child is educated in the school that he or she would attend if nondisabled;

(d) In selecting the LRE, consideration is given to any potential harmful effect on the child or on the quality of services that he or she needs; and

(e) A child with a disability is not removed from education in age-appropriate regular classrooms solely because of needed modifications in the general curriculum. (Authority: 20 U.S.C. 1412(a)(5))



Sec. 300.553 Nonacademic settings.

In providing or arranging for the provision of nonacademic and extracurricular services and activities, including meals, recess periods, and the services and activities set forth in Sec. 300.306, each public agency shall ensure that each child with a disability participates with nondisabled children in those services and activities to the maximum extent appropriate to the needs of that child. (Authority: 20 U.S.C. 1412(a)(5))

* * * * * *

As this issue of the TASH *Newsletter* goes to press, the regulations are barely three days old. The 400+ page document needs to be carefully read and will be reviewed in detail in the next issue of the *Newsletter*. In the meanwhile, you can access the regulations at the following websites:

http://www.access.gpo.gov/su_docs/aces/aces140.html

http://www.ed.gov/offices/OSERS/IDEA/index.html

http://www.wrightslaw.com/law/code_regs/

Index_IDEA_Regs_990313.htm

You can also order a copy for $8.00 by calling the Government Printing Office at 202-512-1800 or you can write to:
Government Printing Office
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Pittsburgh, PA 15250

The regulations are also available in alternative formats.
Individuals with disabilities may obtain this document in other formats (Braille, large print, audiotape, or computer diskette) on request by contacting:
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California AT A CROSSROADS

BY TERRY BOISOT AND KIMBERLY OLSON, ALPHA RESOURCE CENTER OF SANTA BARBARA, CA

In June, 1998 a complaint was filed against Arc California by the Alpha Resource Center of Santa Barbara and three other state chapters. The complaint was filed with The Arc of the United States requesting expulsion of Arc California from the national membership for failing to uphold the principles of The Arc and failing to provide the leadership necessary to ensure the highest quality of life for individuals of all ages with developmental disabilities.

The Arc of the United States reviewed the complaint and found it warranted further investigation of the facts. The Arc of the United States held two fact-finding meetings in California on August 7 and 8, 1998. The meetings were open to all wishing to speak in support or against the complaint.

After review of the evidence, on October 6, 1998 The Arc of the United States found merit in five of the seven charges alleged by the complainants.

The Arc of the United States found evidence that:

1. Arc California Governing Board actively works and advocates against the constitution, bylaws and position statements of The Arc of the United States.
2. Arc California has not promoted the general welfare of people with mental retardation of all ages.
3. Arc California does not reinforce the belief that all "people with mental retardation have the right to make choices for themselves, have maximum control over their lives, and ... be supported in making a contribution to their community."
4. Arc California does not promote the right of all people to be included in their communities.
5. Arc California does not acknowledge the rights of all individuals with mental retardation to exercise self-determination and make vital contributions to the decisions made about their own lives.

The Arc of the United States did not find sufficient evidence that:

- Arc California did not encourage the development of chapters, to advise and support families and friends, and to coordinate and strengthen the efforts and activities of these groups.
- Arc California does not accept the standards of quality as set forth in the position statement of The Arc of the United States.

Arc California adamantly maintains a position of 'not guilty' on all charges filed by the complainants. The Arc California Governing Board has argued that their activities over recent years have been focused on 'choice' for all. The reality and the perception throughout the disability community, the general public, and in governmental agencies is that Arc California is aggressively pursuing the continuation of large congregate settings to the exclusion of, and ultimate harm to, individuals who choose to live in the community.

Following is a summary highlighting the events that compelled our agency, Alpha Resource Center, and three other state chapters to bring a complaint against Arc California, the largest family-based advocacy organization in California.

Background

More than 40 years ago, founding families of the Arc movement were the first to take a stand against institutional care and advocate that community is the rightful place for people with developmental disabilities to live, learn, play and work. Since its inception, The Arc has been a powerful force throughout the country for elevating services and supports for individuals with mental retardation. In California, many remain loyal to the organization because of these positions. Local chapters of The Arc contribute daily to further these objectives.

Alpha Resource Center challenged the state organization on behalf of 150,000 people with developmental disabilities living in California because over time we have seen the leadership in our state lose its strength. It became clear that too many hopes and dreams [of people with disabilities and their families] were being lost.

Frustration with State Leadership Grows

For more than three years the Alpha Resource Center Systems Advocacy Committee addressed concerns within our local community and throughout the State of California. We witnessed our own local advocacy hampered by positions taken by our state leadership, and our state advocacy efforts were crippled by viewpoints that were different from our state organization.

We needed to look at our shared vision for our own community of Santa Barbara, our state of California, and our nation. Our objective — now and in the future — has been aimed at building communities that will welcome everyone, anywhere, at anytime.

Mark Polit, a parent and an advocate, testified at the fact-finding hearings on August 7. He said, "California Arc has exerted leadership to stabilize the population of large state institutions and educate the public that people with severe and profound disabilities need to be protected from their home communities. California Arc has educated the public to the limitations of people with disabilities and not their strengths, their

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California at a Crossroads

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vulnerability and not their aspirations, their failures and not their potential."

From these discussions we generated a resolution that said Arc California will "aggressively advocate for community alternatives to large congregate living centers...." This resolution was presented in January, 1998, and subsequently rejected at a March 5 meeting. It was the opinion of the Arc California's Governing Board that the resolution intended to close developmental centers and was in conflict with the Arc California's Position on Choice.

Dave Denniston, a parent, an Alpha Resource Center board member, and chair of the Systems Advocacy Committee, testified during the August fact-finding meeting that, "We were told by a number of Arc California board members that the resolution would pass if we would only remove the reference to large, congregate living centers. We refused, believing that the money and effort spent on developmental centers was necessary as a reference point - a basis for comparison of institutional versus community supports. Without that point of reference, we believe it just would have been business as usual for Arc California."

During the same meeting on March 5, we became aware of a letter dated February 27, 1998 from the President of Arc California to Quincy Abbot, President of The Arc of the United States. This letter was in response to Mr. Abbot's "President's Perspective" in the Winter of 1997 edition of *"The Arc Today"*.

The President's Perspective article said, "The Arc's individual Position Statements on Family Support, Education, Employment, Where People Live, Recreation and Leisure, and Availability of Community Services and Supports all carry forth the same theme: Inclusion. All people with or without mental retardation have the right to be fully included in their diverse communities. Our movement to eliminate segregation wherever it occurs will continue. Residential institutions, sheltered workshops, segregated schools, segregated classes within regular schools, segregated leisure programs - all must go."

The President of Arc California wrote to Mr. Abbot, "As President of Arc California, I find myself in a very difficult position. I am a firm believer in maintaining a strong national organization, but I know that my board will find it impossible, as do I, to reconcile supporting an organization whose goals seem to be in direct opposition to both our mission statement and our position on inclusion." The Governing Board of Arc California voted to commend the President for her letter.

Alpha Resource Center and Other Advocates Take Action

At this point, Alpha Resource Center felt it could no longer spend time and energy to influence the leadership of Arc California, nor could it remain a silent party to an organization that fails to embrace a vision of the future in which all individuals are valued members of their community. Alpha was not alone in its frustration.

Bruce MacKenzie a parent and a founder of CASA, a family-based advocacy organization, submitted written testimony to the fact-finding team from The Arc of the United States. In part it reads, "CASA came into existence in September of last year [1997] when we grew weary of the fact that there was no statewide parent/families/consumers advocacy organization that spoke in Sacramento for the community families and consumers. Arc California has not represented our families and children for several decades. We thought it was time to form our own group to perform the advocacy that Arc California has failed to do for so many years."

The testimony of Bill Coffelt, parent and a founder of The Oaks Group that spearheaded the *Coffelt v. DDS* litigation that resulted in development of community living arrangements for thousands of Californians said it best, "...it should come as no surprise that I, as a member of The Arc of the United States and President of The Oaks Group, an organization formed solely to counter the positions and resolutions of Arc California, would stand before you supporting this complaint. However, I feel that the most compelling testimony justifying expulsion of Arc California will come from Arc California supporters themselves."

Individuals speaking at the fact finding meetings in opposition to the complaint continued to defend the actions of Arc California and did not refute our allegations. Those speakers included a lobbyist for the California Association for State Hospital Parent Councils for the Retarded (CASH-PCR), the attorney representing Arc California, Dr. Cable from Fairview Developmental Center, and Dr. David Strauss, a statistician whose mortality studies are well known.

After much deliberation the executive committee of Alpha Resource Center made the decision to recommend to our board and membership to withdraw from Arc California, although this meant we would forfeit our membership in The Arc of the United States. Simultaneously we requested The Arc to revisit their bylaws which prohibit independent affiliation when a state chapter is in existence. The Arc of the United States responded by saying, "...it is my belief and that of the other officers that such a change may not be the most effective way to deal with the problem. Further, we think it would likely create so many other problems, that it is not a viable route. Your chapter's complaint, as we understand it, appears to lend itself to the filing of a formal complaint against your state chapter...."

Within a few days Alpha Resource Center received calls from three other local chapters supporting our position. Under a common vision, the four chapters worked as a team and developed a strategy. One team researched and documented complaint allegations, the other team developed the constitution and bylaws for a new family-based statewide advocacy organization. From this group was born The California Alliance for Inclusive Communities (CAIC), advocating with and on behalf of people with developmental disabilities and their families.

In part the mission statement reads: "The California Alliance for Inclusive Communities is a statewide family based organization that is committed to advocating for high quality community-based services and supports for individuals with developmental disabilities and

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California at a Crossroads

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their family members throughout the individual's life span." This mission statement represents the commitment we had been unable to obtain from the Arc California Governing Board.

An Agreement Is Negotiated

On October 7, 1998 The Arc of the United States, Arc California, Alpha Resource Center and the three state chapters negotiated an agreement that would facilitate significant changes within Arc California. Arc California faced expulsion from The Arc if the agreement was not ratified by its governing board. On November 7, Arc California Governing Board ratified the agreement as follows:

PREAMBLE:

Arc California recognizes the importance of The Arc of the United States' position statements in setting the national agenda for people with mental retardation and their families.

Arc California reaffirms its commitment to the general welfare of people with mental retardation of all ages and recognizes that this is the essence of all of The Arc's activities.

Arc California recognizes and regrets that some local chapters feel disenfranchised. Arc California recognizes its responsibilities as a state chapter to welcome and work with local chapters.

Arc California will work in good faith to resolve the issues raised by the local chapters and ensure that all member voices are heard, considered and respected in the deliberative process of the Board of Directors.

ARC CALIFORNIA AGREES TO:

1. *Rescind the letter dated February 27, 1998 sent to Quincy Abbot, President of The Arc of the United States.*
2. *Go on record to work toward implementation of the position statements of The Arc of the United States.*
3. *Work with The Arc of the United States to initiate a waiting list campaign for California.*
4. *Make community-based support and services the highest priority for Arc California, to publicly announce this priority and to work to sponsor and support specific legislation to foster high quality community-based services for people with mental retardation and their families.*
5. *Initiate a program to foster self-determination for people with mental retardation living in California.*
6. *Actively pursue and support the California advocacy program for people with mental retardation living in developmental centers to facilitate movement to community-based services consistent with their Individual Program Plan.*
7. *Publicly announce the end of the moratorium and reaffirm its commitment to community-based services and supports.*
8. *Re-examine its role as plaintiff in the Richard S. lawsuit using new information and analysis regarding the issues of the case.*
9. *Develop a plan for improving the governance of Arc California using an external consultant with expertise in organizational management and models of governance of other state chapters of The Arc. This plan should include:*
   a. *a way to reduce the size of the Board of Directors based on the proportion of the state's population of persons with mental retardation;*
   b. *term limits for board members;*
   c. *regular and on-going board development; and*
   d. *methods to ensure that all local chapters are vested in Board deliberations and that minority voices are heard.*
10. *Send two Arc California board members to the 1999 leadership training session.*
11. *Seek approval of the agreement by the Arc California Board on or before November 15, 1998 and communicate this approval to The Arc of the United States President on or before November 25, 1998. A representative of The Arc of the United States will be present at the Arc California board meeting to discuss this agreement.*
12. *Submit a progress report to The Arc of the United States President on compliance with the above on January 15, 1999. Appropriate on-going follow-up will be determined by The Arc of the United States Board of Directors.*

Arc California will continue to face expulsion from The Arc if it fails to work in good faith in its performance of the agreement. The Arc has given us hope that California is now in a position to build a powerful force advocating for and "securing for all people with mental retardation the opportunity to choose and realize their goals of where and how they learn, live, work and play". We hope Arc California will rally behind the philosophy built into the agreement and work in a united way to promote the position statements of The Arc. The Alpha Resource Center will work in good faith with Arc California in implementing the agreement by becoming members once again, serving on the governing board and on the implementation committee.

Terry Boisot is President of Alpha Resource Center of Santa Barbara and has served on the Board of Directors since 1993. Prior to that, she served as a advisory member to the Family Resource Center, a parent network and resource center. Terry is a parent to Michelle, age 12 and Ben, age 9. Ben is deaf, blind, and developmentally and physically disabled.

Kim Olson is Executive Director of Alpha Resource Center of Santa Barbara. She has been employed by Alpha for 20 years. Kim currently chairs an advisory committee to the Tri-Counties Association for the Developmentally Disabled and is also a board member of the Central Coast Assistive Technology Center. Kim recently resigned her position as president of the California Conference of Executives of the Arc due to the complaint filed against Arc California.

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Developing a Shared Understanding: Paraeducator Supports for Students with Disabilities in General Education

BY MICHAEL F. GIANGRECO, EILEEN CICHOSKIKELLY, LINDA BACKUS, SUSAN W. EDELMAN, PRISCILLA TUCKER, STEVE BROER, AND CHRISTOPHER CICHOSKIKELLY, CENTER ON DISABILITY & COMMUNITY INCLUSION-UNIVERSITY OF VERMONT; AND PAM SPINNEY, FAMILY & EDUCATIONAL SUPPORT TEAM, VERMONT DEPARTMENT OF EDUCATION

Introduction

In order for groups of people to become effective teams it is vital that they develop a shared understanding of the underlying beliefs, values, and principles that will guide their work together. This shared understanding evolves over time as members learn about each other, spend time together, and engage in the work of their group.

Having a shared understanding provides a basic structure within which teams:

- develop common goals;
- determine actions that will lead toward the attainment of their goals;
- ensure that their actions are consistent with their beliefs; and
- judge whether their efforts have been successful.

In essence, having a shared understanding helps team members develop their collective vision of the direction in which they would like to head. Therefore, a shared understanding is a statement of what is aspired to, rather than necessarily what currently is. In seeking to establish the what, prior to the how, developing a shared understanding is an initial step that must be followed by effective planning, implementation, and evaluation if the aspirations of the team are to be realized.

What constitutes an appropriate level of training to be an effective paraeducator[1] is currently a topic of national debate. However, there does seem to be widespread consensus that some level of orientation and training is required for individuals to be effective paraeducators. While some states have developed standards for paraeducators or enacted certification requirements, many have not. Under the provisions of IDEA, it is the responsibility of each state and local education agency to ensure that "qualified personnel" are working with students in their schools.

This article lists a set of statements that reflect the shared understanding of the authors regarding paraeducator supports for students with disabilities in general education classes. This shared understanding is based on our collective personal and professional experiences as parents, community members, advocates, paraeducators, teachers, special educators, related services providers, and administrators. We have combined those experiences with what we have learned from educational literature and research.

In presenting the following set of statements it is not our intention to suggest that these are the only, best, or correct components to be included. Rather we present them as our thoughts at this point in time, with the knowledge that they have changed since we first drafted them and we expect that they will continue to evolve. We hope that they will be helpful to other groups who are interested in paraeducator issues and foremost are interested in quality education for all students. In this context they can be used as a starting point in developing a shared understanding among the people in your own setting.

Ask yourself what you think about the items we have listed. How might you reword them to reflect your own collective thoughts and match your own situation? Are there any you would delete or add to those listed here? The set of statements included in one's shared understanding can also be used as a practical tool. It can help teams identify and prioritize their needs by collecting facts about the status of each component of the shared understanding using a self-assessment format. An action-planning

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[1] Throughout the remainder of this article you will notice that we have used the generic term "paraeducator" to refer to individuals who are trained to work with, and alongside, educators in classrooms and other educational settings to support the education of students with and without disabilities in a variety of capacities (e.g., physically, socially, instructionally). Paraeducators are school employees who, while not hired to work in the capacity of a professional position (e.g., teacher, special educator, related services provider), do provide important supportive services in schools under the direction and supervision of qualified school personnel.

We recognize that the terms used to refer to these school personnel vary widely and often are used interchangeably (e.g., teacher assistant, teacher aide, instructional assistant, program assistant, educational technician, job coach). Individuals with these various job titles are referred to in the Individuals with Disabilities Education Act (IDEA) as "paraprofessionals." We support the use of locally adopted job titles that are descriptive of the work done by these school personnel and which are designed to establish or increase respect for individuals who are providing these vital educational supports to students.

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process that includes this application of a shared understanding is currently being developed and field-tested by staff at the Center on Disability and Community Inclusion in conjunction with the Vermont Department of Education and local schools.

Acknowledging Paraeducators

1. Paraeducators should be considered members of the educational teams for the students with whom they work. These teams typically consist of the student (when appropriate), the student's parents, teachers, special educators, and others as needed on an ongoing or situational basis (e.g., related services providers, school nurse, bus driver, mentors with similar disabilities as the student).
2. Paraeducators provide important services that influence student learning, social/emotional development, and inclusion.
3. Paraeducators should be valued, appreciated, and recognized for their unique competencies, hard work, and contributions to the classroom, school, and community.

Orienting & Training Paraeducators

4. Paraeducators should receive orientation (e.g., information about the student, classroom, and school) and entry-level training prior to working directly with students (e.g., family-centered principles; multicultural and other diversity issues; teamwork; inclusive education; roles and responsibilities of team members; principles of learning, to name a few).
5. Paraeducators should receive ongoing, on-the-job, training to match their specific job responsibilities and assignments.
6. Paraeducators should have access to ongoing learning opportunities, in addition to their on-the-job experiences (e.g., workshops, courses, internet study), that promote their skill development in relevant areas (e.g., supporting students with challenging behaviors; approaches to literacy; use of technology; needs of students with low incidence disabilities) and have input into what training they need.
7. Paraeducator training experiences should be designed to allow individuals to gain continuing education or college/university credit.

Hiring & Assigning Paraeducators

8. Practices should be established to recruit, hire, and retain paraeducators.
9. Substitute paraeducators should be recruited and trained to ensure that a student's access to education and participation in his/her educational program is not unduly disrupted when the regular paraeducator is unavailable due to occurrences such as illness, injury, personal leave, or professional development.
10. Each school should have an agreed upon team process and criteria for determining whether paraeducator support is needed for students with disabilities to receive an appropriate education.
11. When paraeducator support is determined to be necessary for a student, a written plan should explicitly clarify the nature and extent of the support and explain how it is referenced to the student's educational program (e.g., IEP goals, general education curriculum).
12. In most circumstances it is advisable to assign paraeducators to classrooms or instructional programs rather than to an individual student. In the rare cases when a paraeducator is needed for an individual student, efforts should be made to ensure that paraeducators provide supportive, rather than primary or exclusive, services.
13. When administrators make work assignments and re-assignments to meet students' educational needs, it is advisable to gain input directly from paraeducators and other team members (e.g., parents, teachers, special educators, related services providers) to understand factors that may influence job performance, job satisfaction, and reduce burn-out (e.g., variety of duties; interpersonal dynamics; individual skills and interests; longevity with a particular student).
14. Paraeducators should have an accurate job description that outlines their roles and responsibilities. This job description should be commensurate with the paraeducator's skill level as it pertains to students both with and without disabilities.
15. Paraeducators should be compensated in accordance with their level of education, training, experience, and skills.

Paraeducator Interactions with Students & Staff

16. Paraeducators are expected to demonstrate constructive interpersonal skills with students and other team members (e.g., use respectful communication when speaking with or about others; maintain confidentiality; ensure dignity when providing personal care).
17. Paraeducators should develop and demonstrate attitudes and work habits that encourage student independence; foster appropriate interdependence; promote inclusion and peer interactions; enhance each students' self-image; and prevent the unintended negative effects often associated with the potential over-involvement and proximity of adults.

Roles & Responsibilities of Paraeducators

18. Within the classroom, on a day-to-day basis, the classroom teacher is the instructional leader and interacts directly on an ongoing basis with students who have disabilities. Paraeducators, under the direction of the teacher and special educators, function as vital support to students under the direction of the teacher and special educators.

19. Teachers, special educators, and related services providers (e.g., speech/language pathologists, physical therapists, occupational therapists, school psychologists) have the ultimate responsibility for ensuring the appropriate design, implementation, and evalua-

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tion of instruction carried out by paraeducators.

20. Paraeducators should be informed about the educational needs (e.g., IEP goals and objectives; components of the general education curriculum) and characteristics of the students with whom they work, as well as classroom and school practices and routines.
21. Paraeducators should have opportunities to contribute to the development of the educational program, instructional plans, and activities created by each student's educational team, but should not be given sole responsibility for these and related activities.
22. Some of the primary functions of paraeducators are to: support the implementation of instructional programs; facilitate learning activities; collect student data; and carry out other assigned duties (e.g., supervise students at lunch or recess; provide personal care supports to students; do clerical tasks) based on plans developed by the teachers and special educators.
23. Times and mechanisms should be established to allow opportunities for paraeducators to be oriented to teacher's plans, report on student progress, ask questions, and offer their perspectives.

Supervision & Evaluation of Paraeducator Services

24. Paraeducators should receive ongoing supervision and regular performance evaluations which are based on their job descriptions and apply clearly defined processes and procedures.
25. Supervisors of paraeducators (e.g., teachers; special educators) should be trained in effective supervisory practices through preservice, inservice, or graduate training.
26. Paraeducator services should be considered in school and district-level school improvement action-planning to ensure that appropriate services are available and effectively utilized.
27. When a student is receiving support from a paraeducator, an evaluation plan should be established to determine, if possible, how and when paraeducator services can be faded through increased student independence or replaced by more naturally occurring supports (e.g., classroom teacher, peers).
28. School districts should develop ways to evaluate the impact of paraeducator services on individual students, classrooms, and staff.

For additional information on the points highlighted in this article, visit the following websites:
http://www.uvm.edu/~uapvt/parasupport/
http://www.uvm.edu/~uapvt/paraprep/

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DISABILITY HUMOR: MOVING BEYOND "THAT'S NOT FUNNY!"

BY MARA SAPON-SHEVIN AND ROBIN SMITH

How often have you heard someone tell a joke about disabilities and not known what to say? Have you ever been unsure whether disability humor was oppressive or liberatory? Have you found ways to laugh about and around disability issues that feel good to you?

Our work in this area originated at a TASH conference in 1995. One of the evening events featured the work of two performers/comedians. Mara (co-author of this article) was asked to function as the Emcee. The first performer, Cheryl Marie Wade, shared an incredibly powerful performance piece featuring her poetry, movement, singing and storytelling related to growing up as a disabled woman in society.

The second performer was a comedian, a young man who uses a wheelchair following an automobile accident. Some of the comedian's jokes were about the oppression of people with disabilities or made note of humorous/ironic moments in the lives of people with disabilities. For example, "I go into the restaurant in my wheelchair, and there's a sign that says 'PLEASE WAIT TO BE SEATED', and I wonder — am I going to get in trouble?" Unfortunately, much of the humor was problematic — the comedian made fun of people with Asian names, fat people, different ethnic groups and people "so retarded" they couldn't read the seat pocket information on the plane. The several people in the audience who carried that label were the butt of his jokes. Many people in the audience laughed; others looked very uncomfortable.

We both had a hard time with the experience:

Mara: As emcee, I was very troubled. What should I do? Should I stop the performance and use a hook to remove the comedian? Should I simply stand by and be party somehow to the oppression of people in the audience as well as other people with disabilities and those of different ethnic and racial groups? As someone who has committed my life to ending oppression in general and handicapism in particular, this was an incredibly difficult moment. I exchanged worried and questioning glances with others in the audience who wondered what to do as well and clearly wondered what I would do in this situation.

Robin: I've told Mara that the evening's real entertainment was watching her squirm. What I didn't share with her was that I also felt joy that I wasn't the emcee. As a person who has struggled with, and sometimes successfully interrupted such "humor," I had no idea what to do or how to do it. Could I stand up and say, 'Something isn't right here ..." or "Let's talk about this?"

After the presentation, we (the authors) talked at length. We wondered why people laughed, especially in an audience full of advocates and self-advocates on disability issues. What distinguished the jokes we liked from those we didn't? Why was there not general agreement that the put-downs weren't funny? And, most importantly, what should we do about it? We decided that although we were unable to change that evening's event, we could take on the issues of disability humor at future TASH meetings and elsewhere. Since then, we have presented on this topic several times, for various audiences, learning more with each presentation. This article shares some of our insights about the uses and abuses of disability humor.

We typically begin by saying that as advocates for people with disabilities, we share two underlying assumptions: (1) we are committed to ending oppression of people with disabilities and to educating the public about disability issues; and (2) we believe humor can be extremely helpful and that it is extremely important to be able to laugh and not take disability too seriously. We feel that humor can and should be part of the educational and advocacy work that we do.

Categories of Jokes

This project has led us to collect as many examples of disability humor as we could find. We searched the Internet, periodicals and newspapers, and included within our purview cartoons and jokes (including some cartoons and phrases printed on T-shirts by Dan Wilkins). Although our search has by no means been exhaustive or even systematic, after reviewing many examples of jokes and cartoons about disability issues, we have identified five general categories. These are not mutually exclusive, and often a joke or cartoon fits in more than one place. Nonetheless, this sorting system has allowed us to raise issues in a helpful way. For each of these categories, we will explain how we define it, give a few examples, and then talk about the effects and/or uses of this kind of humor.

1. Political/Consciousness Raising: Jokes in this category are those which can help the audience to understand any of the political, economic or values issues associated with disability. These jokes are rarely in the "ha ha" category, but are more likely to lead to a sharp intake of breath and an "aha - I never thought about it that way."

For example, one cartoon shows a combination electric chair/wheelchair with the text: "Kevorkian! Electric Wheelchair Company .... When you need us ... We'll be there" (Scott Chambers,

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Mouth magazine). For those unfamiliar with the debate about the ways in which the assisted suicide movement is very worrisome to people with disabilities (the Not Dead Yet Movement is an example of that position), the cartoon allows us to explain the dangers of "helping" people with disabilities to kill themselves as opposed to fighting for adequate housing, health care, employment, friendship and community services.

Another cartoon in this category is pictured on a T-shirt by Dan Wilkins. It shows a wheelchair symbol wearing an Indian headdress with the logo "Camp Can't-Feel-My-Legs" and reads: "A special place for folks who are quite severely buggered up, i.e. those with spinal cord injuries, ms, md, spina bifida, cp, post-polio, circulatory problems, and amputations (except those who think they can feel their legs), aw heck, them too." In some ways crude, this cartoon raises the politics of special segregated recreational opportunities for people with disabilities and promotes a discussion of how and where we serve children with disabilities. Cartoons or jokes in this category can be used to help people become more aware and better advocates.

2. **Normalizing:** Jokes or cartoons in this category are those which encourage the audience to understand that people with disabilities are "real" people, typical in many ways, and with most of the same interests, desires, strengths and weaknesses of people without disabilities. For example, one cartoon by John Callahan shows an after-hours restaurant in which the chairs have been turned upside down on the tables. At one table, four wheelchairs have been turned upside down — with their users still in them! The caption reads: "When Quads Won't Leave." Although not everyone agrees that this joke is funny, it does allow the audience to think and talk about the fact that people in wheelchairs do go to bars, do have fun, and can also be resistant and problematic — just like other people!

3. **Another joke in this category:** Question: "Why did the blind man give up sky diving?" Answer: "It scared the hell out of his dog." A cartoon from Accent shows a couple in wheelchairs contemplating the ramp and access symbol at Lovers' Leap. Jokes/cartoons in this category support a discussion of ways in which people with disabilities should and can be included in the "normal" range of vocational, recreational and intellectual pursuits.

4. **Challenging Stereotypes and Assumptions:** We include here jokes which provoke the audience to reconsider their beliefs and assumptions about people with disabilities, the ways in which services are provided, the language which is used in describing them, and so on. One cartoon, for example, shows a giant pencil standing on the street corner holding a cup full of blind people in one hand and a fistful of dollars in the other. The cartoon asks us to think about charity models of providing for people with disabilities through the irony of the giant pencil.

In another cartoon from Accent, a person in a wheelchair waits on the corner for the light to change. There are two light-up signs; one says "(DON'T) WALK," the other, "(DON'T) WHEEL." Another cartoon shows a man on a desert island who has spelled out, with rocks, "HLEP." A helicopter is passing overhead and one of the pilots says to the other, "I can't make it out either; let's go home." Although at first glance this cartoon might appear to be making fun of people who are dyslexic or illiterate, we have used this cartoon to initiate a discussion of the ways in which communicative competence involves the repertoires of both the "speaker" and the "listener." Learning to understand people whose communication is non-standard or difficult is an important ethical and pedagogical issue. We can ask, "In this cartoon, who had the real problem? Who needs to change?"

5. **Cheap Laugh:** Jokes/cartoons in this category are those at which we laugh often because they are clever — and then realize, perhaps only much later, that the joke is in some ways at the expense of people with disabilities. For example:
Q: "What do you call an armless person floating in the water?
A: Bob.
Q: . . . Cooking on the grill?
A: Patty.
Q: . . . Hanging on the wall?
A: Art."
Some of the old Helen Keller jokes also fall into this category:
Q: "What did Helen Keller do when the house caught on fire?
A: She screamed her hands off." Discussing jokes in this category allows us to ask, "Why did we laugh?" "What is it about this topic that makes us uncomfortable?" "How might we work on that discomfort?"

6. **Veiled Vile:** Entries in this category are very close to hate speech. Often these jokes or cartoons use the medium of "humor" to share vicious, hostile and often deadly information about people with disabilities. For example, on list reads: "Why Beer is Better than Retarded People" and includes the entry, "Beer doesn't have to be sterilized." Another entry is a web site about midget throwing which includes the comment, "The creator of this site hates midgets. As such this web site reflects this. If you are a midget or dwarf, or you conspire with midgets and dwarves, then you will NOT enjoy this site. So my advice to you is LEAVE NOW! GO AWAY! If you go beyond this disclaimer you will probably be offended."

Attitudes or beliefs like this would be unacceptable to most people, but because they are couched as "humor" they are considered, somehow, more acceptable. Exploring "humor" in this category allows us to discuss the ways in which humor against a particular group is often the first step in an escalating program of hatred and violence (for example, cartoons about Jews in pre-Hitler Germany). We can talk about the ways in which humor can be dangerous and, if left unchecked, can desensitize people to the oppression and real dangers of the oppression.

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How Can We Tell What's Funny?

In trying to decide how we feel about specific jokes and engaging the audience in that discussion, we have found it helpful to ask several questions.

1. In the presence of a person with this disability, would you feel comfortable sharing this joke? Hearing this joke?

2. Does this joke make you feel like you have something in common with a person with this disability? Closer to people with this disability? More understanding of this disability? More relaxed with people with this disability?

3. Or does this joke make you feel "they" are irrevocably different? More distant from "them"? That they are somehow less than human? Does the joke provide or reinforce incorrect information about the disability or make you tense or awkward in the presence of a person with this disability?

4. Is this joke laughing AT people with disabilities or WITH them? Is the joke exploitative? Who benefits from humor of this type?

What Do We Do About Inappropriate Humor?

Once we have decided that we are uncomfortable with a joke or comment, what do we do? Strategies for interrupting or contradicting the insults are difficult to formulate. There are many variables and no one strategy will be appropriate or effective in every situation. Context matters: Who is the joke teller? Who is the audience? What's your relationship with the person telling the joke? Who are you (are you a person with or without a disability) and how are you viewed by others?

There are no perfect solutions, but we offer here a few strategies that some people have found effective.

- **Personalize it: take it personally:** Share the long-range impact on people. "I used to think that way (make those remarks) but then I made friends with someone who (state the disability) and found out how much they were hurt by that"; "I have some friends with that label and they are struggling not to apply all the insults to themselves that the culture puts out." You might want to indicate that you are close to someone just insulted and so feel hurt yourself.

- **Engage the person in a dialogue:** Ask the joke teller a question about what they just said: "What does retarded mean?", "What do you know about people with AIDS?" Sometimes you can get farther if you don't put the joke-teller down (avoiding embarrassment and guilt) but instead ask a question: "I've heard that term used several times lately and I've been wondering why people use it? What do you think?" Enlist their help in interrupting oppression and thinking about how it operates on the personal, cultural/social, and institutional levels.

- **Share accurate information:** "Did you know that...?" "Actually, I have a friend with Down syndrome and he's reading as well as other kids in his grade." Question the information contained in the insult, for example, "Where did you hear that?", "How do you know that's true?" Remember that the contributions and strengths of most "minority" group members have been excluded from our education. Share what you know, working from the stance that the joke teller is ignorant rather than malicious (even if you believe otherwise!)

- **Be light-hearted and relaxed; make a joke yourself:** "Hey, some of my best friends are...", "Oh, no, call the humor patrol — Mark's telling bad jokes again." Be creative in your response. Sometimes laughter can clear the mind and pave the way for an attitude shift.

- **Refuse to participate in the expected way:** Suddenly become serious and say, "I didn't think that was funny.", "What was funny about that?", "I don't get it (with a puzzled look)." Force the person to explain or retell what they said. Often they will realize they've said something inappropriate. Hold the joke teller to a high standard: "I know you to be such a caring person who would never hurt someone, do you know how hurtful that remark is?" Punishment and guilt are not generally effective. There are times when "Don't say that around me" is a useful and viable option, but save this as a last resort unless you're in a situation where the behavior is so intolerable (in the presence of young people, for example) that simply shutting down that person makes sense.

- **Model self-appreciation and appreciation for differences in others:** Gandhi said, "Become the change you want the world to be." Take complete pride in your own body, including your size, your looks, your assorted physical conditions and differences. Respond to friends' complaints about their gray hair or their weight with authentic appreciation of them the way they are. Invite others to share pride in their backgrounds and accomplishments.

Our work in this area is far from done. We welcome contributions of jokes, cartoons, and strategies for dealing effectively with humor, as well as stories of times/ways in which you've handled such situations with grace or success. Most importantly, we ask you to enjoy the process, take risks and realize that the world we create for people with disabilities is the world we create for all of us.

Mara Sapon-Shevin is Professor of Education and Robin Smith is a doctoral candidate, both at Syracuse University.

Please send jokes and cartoons to: Mara Sapon-Shevin or Robin Smith, 150 Huntington Hall, Syracuse University, Syracuse, N.Y. 13244-2340; or email to: msaponsh@mailbox.syr.edu or rmsmith@mailbox.syr.edu

U.S. Supreme Court Requires School District To Pay For Nursing Services For Student With Complex Health Care Needs

BY DONNA LEHR, PH.D.

On March 3, 1999 the US Supreme Court handed down an important decision (Cedar Rapids Community School District v. Garret. F., 1999) that will affect the lives of many school aged children who have complex health care needs and require health care services while at school. By a vote of 7 to 2, the Justices decided that a school district must pay for health care services for a student who requires ongoing ventilator monitoring and care, tracheostomy suctioning, and clean intermittent catheterization.

Ever since the enactment of PL 94-142 in 1975 (now known as IDEA), there has been considerable debate surrounding the question of who is responsible for paying the cost of health care services for students with complex health care needs who began attending school in increasing numbers. Debates have occurred within IEP teams, in mediation, in administrative hearings, and in the courts.

Central to this debate has been the interpretation of the terms "related services" and "medical services" in IDEA (Lehr & Noonan, 1989; Lehr, 1996; Thomas & Hawke, 1999).

> Related services are defined in IDEA as: transportation and such developmental, corrective, and other supportive services (including speech pathology and audiology, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, social work services, counseling services, including rehabilitation counseling . . (20 U.S.C. Sec. 1401 (a) (17)).

> Medical services are defined as being solely "for diagnostic and evaluation purposes" (20 U.S.C. Sec. 1401 (a) (17)).

In some cases, students' needed services have been considered to be "related services" and the cost of those services have been assumed by school districts. For other students, sometimes with identical health care needs, the services have been considered to be "medical" in nature. Since the services were not for the purpose of diagnosis or evaluation, the districts have not assumed financial responsibility for providing those services to the students (Lehr & Noonan, 1989; Lehr, 1996; Thomas & Hawke, 1999). Those students have been educated at home, or if they attended school, their health care services were paid for by the parents, the parents' insurance, or public insurance (e.g. Medicaid) (Lehr, 1996).

In an attempt to provide some clarification, in 1983, the Department of Education defined school health services as related "services provided by a qualified school nurse or other qualified person" (34 C.R.F. Sec. 300.13 (b) (10)) and medical services as "services provided by a licensed physician to determine a child's medically related disability that results in the child's need for special education and related services" (Sec. 300.13 (b) (4)). Despite this attempt, ambiguity has persisted.

In 1984, the US Supreme Court rendered a decision that provided some guidance to parents and schools regarding the financial responsibility of schools for health care services. In Independent School District v. Tatro (1984), it was established that schools were responsible for paying the costs associated with performing clean intermittent catheterization (CIC) for a young student with spina bifida. The Court used two criteria to decide the case. First, it established that the health care service needed was necessary to enable the student to benefit from special education and therefore a "related service," and second, it established that the service was not one that was medically excluded by IDEA, which was described as a service that must be provided by a physician.

"This case is about whether meaningful access to the public schools will be assured, not the level of education that a school must finance once access is attained."

The Tatro decision only addressed the health care procedure of clean intermittent catheterization. Amber Tatro required CIC on a fixed, once-a-day basis and training necessary to administer the procedure was considered to be minimal. By contrast, the health care procedures other students have needed, such as tracheostomy suctioning, ventilator care and gastro-nasal tube feeding, have been considered much more complicated, and the training necessary to become competent to provide the services, more extensive. Sufficient differences in the nature and extent of the services as compared to CIC, led some courts to find the criteria established in Tatro to have had lim-

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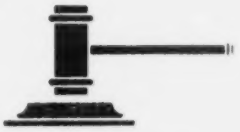
ited usefulness for determining financial responsibility of school districts. Consequently, confusion regarding schools' obligations has continued and analyses of court cases reveal "conflicting interpretations of federal statues and regulations" (Thomas & Hawke, 1999, p. 226).

The case recently decided by the US Supreme Court (Cedar Rapids Community School District v. Garret F., 1999) focused on a high school student whose spinal cord was severed at age 4 due to a motorcycle accident. The accident left him paralyzed and in need of health care services including urinary track catheterization, tracheostomy tube suctioning, ambu-bagging during suctioning, and ventilator monitoring. Initially Garret's family assumed responsibility for his health care needs in school by providing it themselves or by paying for others to provide it. In 1993 they requested that the school district pay for the services. The district refused.

The district argued that the health care services Garret needed were medical in nature and not a related service. They concluded that the district was not required to pay for the services under the IDEA medical exclusion provision, since the needed services were not necessary for purposes of diagnosis and evaluation. The parents challenged the school district's decision and requested a hearing with the Iowa Department of Education. The hearing officer agreed with the parents that the school district should be responsible for the cost of providing Garret's health care services while he attended school. The district appealed the decision of the Department of Education in Federal District Court, where the Department of Education's decision was affirmed. The district then appealed the case in the Eighth Circuit Court of Appeals. Again, the previous decision was affirmed, holding the school district as responsible for paying for Garret's health care while he attended school. A clear distinction (called a bright-line test) was made by the Eighth Circuit Court of Appeals: if the services must be provided by a physician, they do not have to be provided by the district (except in the case of necessary diagnosis or evaluation); if the services can be provided by anyone else, they must be provided by the school.

The school district petitioned and the US Supreme Court agreed to hear the case. The district argued that decisions regarding school district financial responsibility should not be based on a simple, bright-line distinction such as who provides the services but instead should be based on multiple factors "such as whether the care is continuous or intermittent, whether existing school health personnel can provide the service, the cost of the service, and the potential consequences if the service is not properly performed." They presented the case that a logical, common sense approach would lead to a determination that the full time provision of a one-on-one nurse for a student in school is medical in nature, and that a bright-line interpretation is too narrow. They further asserted that the cost and the nature of the care is beyond what was intended to be covered by IDEA.



The Supreme Court decision was clear: school districts are responsible for paying for health care for students who require constant health care services.

The lawyers presenting Garret's case to the Supreme Court argued that the nature of the services Garret required were related services —school health services as defined in the IDEA regulations — necessary for him to benefit from a special education and since they did not have to be provided by a physician, they did not fit the medical exclusion criteria.

The Supreme Court affirmed the lower court's decision that school districts should assume financial responsibility for providing health care services, even when the services are more extensive than CIC. The Justices dismissed the argument that a multifactored test, including costs as a factor, be used to determine a district's responsibility for paying for health care services. While the Justices recognized that a financial burden to school districts may occur, they stated that since IDEA does not use the cost of services as a way of defining the scope and nature of services, cost could not be used to define who pays for services.

The Justices concluded their opinion with the following: "This case is about whether meaningful access to the public schools will be assured, not the level of education that a school must finance once access is attained. It is undisputed that the service at issue must be provided if Garret is to remain in school. Under the statute [IDEA], our precedent [Tatro], and the purpose of the IDEA, the District must fund such 'related service,' in order to help guarantee that students like Garret are integrated into the public schools."

Many are celebrating this decision as a victory for students with complex health care needs in today's schools, assuring students' access to education in school buildings. It will no longer be possible for school districts to refuse to pay for students' necessary health care services, and place students at home to receive their education when other means of paying for the services are not available. Others are concerned about the impact of this decision on school district budgets. In an *amicus curiae* ("friends of the court") brief submitted to the Supreme Court, the National Association of School Boards (1997) argued "local school boards have struggled to meet [the] rising costs" of special education and called attention to Congress' unfulfilled promise of a federal contribution to the costs of special education. They pleaded that the precedent set by a Supreme Court interpretation of IDEA in which the school district was found responsible for the cost of providing for Garret's health care needs would result in an additional burden to already financially strapped districts.

The Supreme Court decision was clear: school districts are responsible for paying for health care for students who require constant health care services. The challenge facing school district administrators is also clear: enabling students to receive an appropriate education in the least restrictive environment in a manner that assures for their health and safety in a

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cost-effective economic fashion. If districts apply the historic models for cost-savings, students with complex health care needs might be placed where the services are (i.e., in schools where there already are nurses) or clustered together in classes where health care services could be provided to several students. These service delivery models are threats to the mandate of educating students in the least restrictive environment. Additionally, cost saving measures such as having unlicensed, less costly personnel administering health care procedures might be appropriate for some procedures, for some students, but may not result in safe care for others. Attention must also be paid to state laws governing the delegation of responsibility for the provision of care to unlicensed personnel (Lehr, 1996; Porter, Haynie, Bierle, Caldwell, & Palfrey, 1997).

Many school districts thoughout the country have already found safe, appropriate and cost effective means for meeting their obligations to students with complex needs similar to those of Garrets. As one district special education administrator said, "When the newspaper reporter called and asked what impact the Supreme Court decision would have on the district, I said 'None. We've been doing it all along.'" With the clarification provided by the Supreme Court, we can look forward to more districts seeking solutions to meeting their responsibilities and an increase in the number of students with complex health care needs who gain access to an appropriate education in least restrictive settings.

Donna Lehr, is an Associate Professor in the Department of Special Education at Boston University where she heads up the programs in the area of severe disabilities. She is the chairperson of the TASH Special health Care Needs Committee. Dr. Lehr can be reached by e-mail at <dlehr@bu.edu>

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TASH NEWSLETTER

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It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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Don't Tread on the ADA

Integration, NOT Segregation

ALSO INSIDE:
Olmstead Analysis, The Importance of Arts Education, Creating New Employment Options, and Canada's Latimer Case

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

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Building communities in which no one is segregated and everyone belongs;

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Eradicating injustices and inequities;

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Supporting research and disseminating knowledge and information;

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Promoting inclusive education;

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Supporting progressive legislation and litigation; and,

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Promoting excellence in services.

From the Executive Director
BY NANCY WEISS

An Update from Central Office

Here's a peek at what's been keeping us busy....

Annual Conference '99 Update:
The Conference Committee is putting together an incredible agenda for this year. Five keynote speakers have been invited so far. They include: Kyle Glosier, a middle school student who speaks via an adaptive device; Diane Coleman, a leader in the Not Dead Yet movement; Anne Donnellan, an expert on new ways to view and understand autism and related disabilities; and Rosangela Berman-Bieler, a leader in international disability issues. Look for more details in future issues of the *Newsletter*.

The Conference Committee has devoted significant attention to identifying strand topics and strand leaders. Strands are planned on the following topics: Advocacy, Aging, Assisted Suicide, Creative/Performing Arts, Communication, Community Living, Criminal Justice, Due Process, Early Childhood, Employment, Ethics/Rights, Family Issues, Governmental Affairs, Guardianship, High School Inclusion, Higher Education, Inclusive Education: best practices, International Inclusion, Leisure and Recreation, Management, Multicultural Issues, Paraeducator/ Paraprofessional Issues, Personnel

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Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about the 1999 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations, (410) 828-TASH, Ext. 100 or rholsey@tash.org
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- **For information on the Journal (JASH), call:** Linda Bambara, Editor-in-Chief, at (610) 758-3271, e-mail: LMB1@lehigh.edu
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An Update from Central Office

Continued from page 2

Preparation, Positive Approaches, Related Services, Research, Self-Determination, Sexuality, Spirituality/Peace, Special Health Care Needs, Students who Severely Challenge Schools, Teacher Preparation, Transition, and Urban Issues. We have received 378 submissions, which is considerably more than we had received last year at this time. Kelly Nelson is busy entering all the proposal information and short descriptions into the computer. Proposals will go out to reviewers over the next few weeks.

Progress on Strategic Plan: The Executive Committee and many other Board members have been working on action plans for the top priorities identified by the Board at their December meeting. The strategic plan will be finalized at the Board's July meeting.

Progress on Revision of Resolutions: An important priority of the Board has been to revise TASH's resolutions to produce a concise set of resolutions that can be distributed broadly and that clearly communicate TASH's beliefs, values and concerns. Committees have been asked to review and revise existing resolutions and to recommend new resolutions related to their committee's topic area. Revised resolutions have been completed in the areas of employment, special health care needs, sexuality and early childhood. The goal is to have all resolutions revised and new resolutions developed for final approval at the July Board meeting.

Web Page Improvements: If you haven't done so lately, check out the new web site: http://www.tash.org. It's been completely revised. TASH's web master, Dan Dotson, has done extensive work to incorporate many of the suggestions we received for improving the web site. The site now includes expanded information on chapters and committees, action alerts, board biographies, staff roles and contact information, all of the current resolutions, opportunities to join on-line, links, exhibitor information, conference information through 2003, and more. The "General Links" section is still under construction. Please suggest additional sites you think TASH should link to and feel free to pass along any feedback.

Sponsorship Activities: Priscilla Newton and Denise Marshall have been working on structuring a range of sponsorship opportunities for this year's conference. See the results of their work at: http://www.tash.org/99conference/sponsorship.htm . This year we are introducing a "virtual exhibit hall" where exhibitors (who pay an additional amount for the privilege) will be able to display their products and services on our web site for a six month period.

NSCIA Conference: Plans are proceeding for the National Spinal Cord Injury Association's conference which we are organizing. It will be held September 26th - 29th at the Marriott at Metro Center, Washington, D.C. Sessions are planned on: independent living, sexuality, life planning, managed care, PAS provision, ventilator users, assistive technology, recreation, assisted suicide, violently acquired SCI, depression, spinal cord injury in children, aging, NIH funded research, MiCASSA, work incentives, Medicaid/Medicare, and housing. More information is available at: http://www.tash.org/calendar/nscia99.html, or at NSCIA's web site: www.spinalcord.org.

Chapter Manual: Linda Rammler has completed work on a draft of a chapter manual. This was a group effort with contributions from Donna Gilles and the chapter representatives that attended the Chapter Leadership Day in Seattle. Copies are being mailed to all Chapter representatives and Board members for review and suggestions. Call to request a copy if you'd like one for review.

Judge Broderick Tape: Work has been completed on the tape of Liz Healey interviewing Judge Broderick, the Judge who ordered the closing of Pennhurst. This tape was made by the Montgomery County Human Services Center. The tape is available for $29.95.

New Book Ideas: We are working on several new book ideas with Doug Fisher, Chair of TASH's Education Committee. Doug suggested that many university professors training new teachers across the country assign the same articles from both JASH and the TASH *Newsletter*. Doug's idea is to publish a book of these classic and important readings which could serve as a textbook for teachers in training. Doug Fisher completed work on a survey that was sent to 180 TASH members who identify themselves as university professors/instructors. The survey seeks information about which JASH and *Newsletter* articles professors currently assign to students and which they would recommend including in a book of readings.

Doug Fisher has also suggested that we publish a "Year Book" after each annual conference. Presenters would be invited to submit the work they presented within thirty days after the conclusion of the conference. A peer review process would be established to select 50-60 "papers" to be published. Conference registrants would have the opportunity to order the year book in advance, at a reduced cost, in conjunction with their registration. It would also be advertised for purchase after the conference. We are seeking bids from publishers for this project.

Education Workshops: Denise Marshall is working on organizing several education-focused trainings. We are going to experiment with two approaches. One is to market trainings to major schools systems. They would pay a flat fee and would take care of publicizing the training and making local arrangements. The other is to coordinate a training jointly with a

Continued on page 21

1999 TASH AWARDS

IT'S TIME ONCE AGAIN TO SUBMIT TASH AWARD APPLICATIONS!

Each year at the annual conference, TASH confers a series of awards that recognize individuals, teams, organizations, or media which exemplify the spirit and mission of TASH. Submit your application (found on the following two pages) today!

◆Who comes to mind when you think of someone who has made a positive difference in the lives of persons with significant disabilities over the past year?

◆Have you recently seen an outstanding media piece that embodies the values of TASH?

◆Do you know of a student enrolled in a doctoral program in education or a related field who demonstrates leadership, advocacy, and commitment to efforts of individuals with disabilities?

◆Is there a team of people working together to improve the quality of life for a person(s) with disabilities?

This is your chance to honor such accomplishments with official recognition. Please take the time to submit an application. Awards will be conferred as part of the TASH Annual Conference to be held in Chicago, December 8-11, 1999. Award applications will be accepted through July 31, 1999. **Please be sure to indicate for which award you are applying on the application, and submit all required documents or information requested for that award.**

1999 POSITIVE APPROACHES AWARD

This award is presented to the person whose contributions have served to advance non-aversive intervention with persons who display challenging behaviors; have demonstrated outstanding efforts leading to the understanding of challenging behavior; and whose actions have advanced the use of non-aversive interventions and progress in the use of positive behavioral supports.

1999 ALICE H. HAYDEN AWARD

This $500.00 cash award will be presented to a doctoral student enrolled in a program in education or a related field and who demonstrates potential for leadership in teaching, scholarship, and service on behalf of people with significant disabilities. The individual needs to have demonstrated a continuing desire in working in partnership with people with disabilities in accordance with TASH values.

1999 MEDIA AWARDS

This award is presented to honor presentations in either print or film, which best promote the inclusion of people with significant disabilities in all aspects of community life, and which have reached a national audience. Criteria for selection include: high quality, accuracy of information, meaningfulness of subject matter, potential for consciousness-raising, and promotion of quality of life for persons with disabilities.

1999 COLLABORATION AWARD

TASH will recognize collaborative teams of persons with disabilities, family members, professionals, community members and/or peers, who are engaged in projects and advocacy efforts to ensure the implementation of TASH values in their local community, or in a way that has affected others at a local, state, regional, and/or national level. The work of the recipients of this award should serve as an inspiration for other community efforts, and demonstrate creativity in supporting an individual or individuals to realize the goals of self-empowerment and full community inclusion.

1999 THOMAS G. HARING AWARD FOR RESEARCH

This award is presented to promote research and scholarly activity in the field of significant disabilities. The award will be presented to the author(s) of a study of particular significance that was published in JASH within the two years prior to the annual conference. The study will have demonstrated scientific merit, and have made an important contribution to the disability field.

1999 TASH AWARD APPLICATION

- Applications due July 31, 1999-

How to Apply:

(1) Complete this application form - front and back- as fully as possible.

(2) Attach a brief narrative discussing why the nomination is being made. Please see the other side of this form for a list of supporting information and materials that must be submitted for the particular award you choose below.

3) Please indicate for which award you are applying. **Check only one award.**

- ❒ Alice H. Hayden Award
- ❒ Collaboration Award
- ❒ Media Award
- ❒ Positive Approaches Award
- ❒ The Thomas G. Haring Award for Research

(4) To be considered, the original completed application and supporting materials must be received in the TASH central office no later than July 31, 1999. Send to:

Awards Committee
TASH
29 West Susquehanna Avenue
Suite 210
Baltimore, MD 21204

Person or Team Being Nominated:

Name of the Individual: _____

Street Address: _____

City: _____

State/Province: _____ **Country:** _____

Zip/Postal Code: _____

Daytime Telephone: (___) _____

Evening Telephone: (___) _____

Is this individual(s) a member of TASH?
❒ **Yes** ❒ **No**

Name of team members (more room on reverse side) _____

Street Address: _____

City: _____

State/Province: _____ **Country:** _____

Zip/Postal Code: _____

Daytime Telephone: (___) _____

Evening Telephone: (___) _____

Is this individual(s) a member of TASH?
❒ **Yes** ❒ **No**

Person Making the Nomination:

Name: _____

Relationship to the team/person: _____

Street Address: _____ **City:** _____

State/Province: _____ **Country** _____ **Zip/Postal Code:** _____

Daytime Telephone: (___) _____ **Evening Telephone:** _____

FAX:(___) _____ **E-mail:** _____

Please provide as much information as possible about the persons who are part of this team. Please use additional paper if necessary.

Name of Team Member:

_____

Organization (if applicable): _____

Street Address: _____

City: _____

State/Province: _____ **Country:** _____

Zip/Postal Code: _____

Daytime Telephone: (___)_____

Evening Telephone: (___)_____

Is this individual(s) a member of TASH?
❒ Yes ❒ No

***

Name of Team Member:

_____

Organization (if applicable): _____

Street Address: _____

City: _____

State/Province: _____ **Country:** _____

Zip/Postal Code: _____

Daytime Telephone: (___)_____

Evening Telephone: (___)_____

Is this individual(s) a member of TASH?
❒ Yes ❒ No

***

Name of Team Member:

_____

Organization (if applicable): _____

Street Address: _____

City: _____

State/Province: _____ **Country:** _____

Zip/Postal Code: _____

Daytime Telephone: (___)_____

Evening Telephone: (___)_____

Is this individual(s) a member of TASH?
❒ Yes ❒ No

***

MEDIA CONTACTS

Please provide on a separate sheet of paper, the names and addresses of local radio, television, or newspaper outlets that would be interested in covering the presentation of the award.

AWARD APPLICATION REQUIREMENTS

Collaboration Award:
1. Attach a narrative which describes: a) the goal of the team; b) the interaction of the team members; c) the roles of the individual himself/herself, the family, peers of the individual, and/or people who provide paid support; d) the outcome of the team's efforts; and e) a brief narrative about the individual or individuals who benefited from the collaboration.
2. Attach at least three (3) letters which support the nomination. These letters should present specific anecdotal information or data which conveys an accurate picture of how this collaborative effort met the criteria for the award.

Positive Approaches Award:
1. Attach a description of the nominee's background in the area of significant disabilities. Please include a resume/curriculum vitae if appropriate.
2. Attach evidence of contributions related to positive behavioral support.
3. Attach three (3) separate one page letters in support of the nomination.

Alice H. Hayden Award:
1. Attach a curriculum vitae outlining your history of: a) higher education (including major, minor, degree, date of completion); b) employment (including dates, duties, name of supervisor); c) research and publications.
2. Also attach 500-1000 word essay which describes: a) your current work on behalf of individuals with severe disabilities; b) your educational and professional objectives.
3. Attach at least three (3) letters which support the nomination. These letters should be from professors who are familiar with your qualifications. The letters should present specific data or anecdotal information which convey an accurate picture of your current achievements and potential for significant contributions to the field.

Media Award:
1. Please provide a brief description of the project, including the medium used (radio, television, newspaper, magazine):
2. If the nomination is in the film category, please indicate the length of the video in minutes.
3. Attach two copies of the nominee's work, or of the specific project being nominated. If the nomination is in the print category, the submission must be neat and legible. If the nomination is in the film category, two video copies (VHS 1/2") must accompany the nomination. The submitted work must be sufficient to demonstrate that the work meets or exceeds the criteria for the award.

Thomas G. Haring Award for Research:
1. To be eligible for the award, the authors' manuscript must have been published in JASH within the two year period prior to the conference. The senior author must agree to be present at the upcoming conference, and to present the contents of the paper as a conference session.
2. To make a nomination, submit a letter which references the article, and addresses the study's significance, scientific merit, and the importance of its contribution to the disability field.

Permission to show video submittals:

If the nomination is in the film category, please complete and sign the following to hereby grant permission to TASH to show:

(Title)_____,

for, but not restricted to, promotion of the TASH Media Awards and the 1999 Annual Conference. Similarly, as it applies to the promotion of the TASH Awards and the 1999TASH Conference, the producers waive any monetary compensation .

Signature: _____

Chicago is Our Kind of Town

Make it your town too! Plan to join us for ***"TASH 2000: Our Turn Now"*** to be held at the Chicago Hilton and Towers. The TASH Conference is where the best of hearts and minds in the disability movement gather to provide and share cutting-edge information that inspires advocates, parents, and professionals alike to understand, support, and creatively move forward toward inclusive lives for all. Whether you are coming from around the world or across the street, this is the place to join over 2500 activists, advocates, educators, and leaders in the quest for full inclusion and participation for all people with disabilities - regardless of their level of disability or need for support.

For more information or questions about the conference agenda please contact:

Kelly Nelson, International Conference Coordinator
Phone: 410-828-8274 x105 Email: knelson@tash.org

"TASH 2000: Our Turn Now"
1999 TASH Conference
Chicago Hilton and Towers ♦ December 8-11

Chicago Hilton and Towers
720 South Michigan Avenue
Chicago Illinois, 60605
312-922-4400 or 1-800-HILTONS
TASH Rates: **$146.00** Single **$171.00** Double/Triple

Look for more information in the May issue regarding official airlines and registration for the 1999 Conference!

ARE YOU A UNIVERSITY PROFESSOR?

TASH has a Student Membership Program!

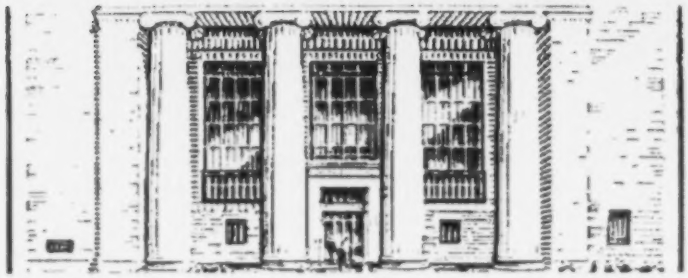
The program was developed through discussions with professors who wanted to encourage professional identity through student membership in a strong advocacy organization while assuring that their students had access to enough issues of JASH for them to be able to complete a variety of journal article review and comparison exercises they assign.

The package works like this:

Professors can either assign TASH membership as one would a text book or package of readings, or can offer it as an option. Either way, if ten or more students join, they receive a discount off the already low student rate. The discount amount increases as the number of students signing up increases.

Regardless of how many students join, TASH provides a year's worth of back issues of the journal to all students signing up under this plan. This means your students will start the semester with a year's worth of cutting edge research on their shelf and can build their collection over the years to come. Under this plan, students receive all of the regular membership benefits during the coming year-in addition to an extra full year's worth of journals.

An introduction to TASH is likely to be one of the most valued resources you can offer students as they enter the disability community in their professional capacities. To receive materials or to learn more about TASH's student membership program, contact Rose Holsey, 410-828-8274, ext. 100 or e-mail: rholsey@tash.org



Pulling the Plug on the ADA?

Olmstead v. L.C. and E.W. at the Supreme Court

BY JONATHAN D. EZEKIEL

On April 21 the Supreme Court heard the case of *Olmstead* v. *L.C. and E.W.*, pitting the state of Georgia and a host of powerful allies against two brave and unknown women (who are now joined by powerful friends of their own).

Despite significant disabilities and years of confinement in state institutions, Lois Curtis and Elaine Wilson have entered the national spotlight and may rewrite American legal history. With its ruling in *Olmstead* v. *L.C and E.W.* expected in early July, the Supreme Court could endorse or dismantle the central tenet of the Americans with Disabilities Act: our society's commitment to end the unwarranted segregation of persons with disabilities.

With the rights of 50 million Americans with disabilities at stake, activists, family members, caregivers, and many in the religious, legal, and medical communities are on full alert.

What has become in some circles a cause celebre began quite simply. Elaine Wilson and Lois Curtis, women with labels/diagnoses of mental retardation and mental illness, were ready to receive treatment in their community, as acknowledged by Georgia's own treatment teams. But for years, according to Atlanta's Legal Aid Society, Georgia steadfastly "refused to release them to a community-based program with appropriate services."[1]

Advocates, later joined by the U.S. Department of Justice, brought suit on the plaintiffs' behalf, arguing successfully in the U.S. 11th Circuit Court of Appeals that segregated placements for persons with disabilities violates Title II of the Americans with Disabilities Act (ADA). Two exceptions were recognized: when integrated treatment in the community unduly burdens a public entity or fundamentally alters its system. Neither of those circumstances applies here.

Georgia has been moving officially, if not actually, toward a community-based system of care for its citizens with disabilities for years and has, by all accounts, a thriving economy. Furthermore, as the district court later declared, the cost of community-based care in Georgia is considerably less than the cost of institutional care.[2]

Moreover, in Olmstead Georgia contradicts its own laws and policies. (The "Olmstead" in *Olmstead* v. *L. C. and E.W.* refers to Tommy Olmstead, Commissioner of Georgia's Department of Human Resources.) Georgia's state code declares that "it is the policy of the state that the least restrictive alternative placement be secured for every client at every stage of his habilitation."[3]

Gov. Roy Barnes of Georgia, in his January 1999 Budget Address, publicly advocated for increased funding for "community-based services which will give...people who are mentally or physically challenged a new lease on life." "Too often," the Governor observed, "we institutionalize patients who pose no threat to society, who could be better served at a lower cost within the communities in which they live."[4]

But in *Olmstead* v. *L. C. and E.W.* the Supreme Court is being asked not to give people a new lease on life, but to proclaim that state-sanctioned segregation and institutionalization of persons with disabilities, even when unnecessary, will henceforth be consistent with the ADA.

The implications of Georgia's refusal to provide integrated care in the community have not escaped the notice of major power centers, both private and public. Calling this case "one of the most important of our generation," the Legal Director of the Judge David L. Bazelon Center for Mental Health Law, Ira Burnim, says a defeat in Olmstead "could be a mortal wound to the Americans with Disabilities Act."

> Neither the ADA nor *Olmstead* v. *L.C. and E.W.* requires deinstitutionalization. What they do require, and what the Court should endorse with its full legal and moral authority, is the fundamental premise that persons with disabilities should not be needlessly forced into services or programs that are isolated and segregated from the rest of society.

Twenty-six states have publicly supported Georgia in either asking the U.S. Supreme Court to hear the case, or (once that was accomplished) in an amicus curiae "friend of the court" brief to the Supreme Court.

Not to be outdone, in February 1999, the State and Local Legal Center on behalf of the National Governors'

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Association, the National Conference of State Legislatures, the Council of State Governments, the National Association of Counties, the U.S. Conference of Mayors, and the National League of Cities, et al., filed a brief with the Supreme Court supporting Georgia's position on Olmstead.

Facing formidable opposition, national organizations consisting of persons with disabilities and their advocates have coalesced into a powerful legal and political coalition of their own. After intense lobbying, nineteen of the twenty-six states that publicly supported Georgia have reversed themselves, either declining to sign the amicus brief to the Supreme Court or dissociating themselves from that brief after signing it.

Countering the briefs on behalf of Georgia are briefs supporting Lois Curtis and Elaine Wilson, filed by the following:

- *Fifty-eight former state commissioners and directors of state mental health and developmental disabilities departments;*
- *Ten organizations of activists who are consumers of mental health services and survivors of psychiatric illness—e.g., the National Mental Health Consumers' Self-Help Clearinghouse—and eight individual consumers/survivors;*
- *Organizations of persons with disabilities, including Self-Advocates Becoming Empowered, three-fourths of whose 20,000 active members "were once segregated into institutions and now are not";*
- *TASH, ADAPT, and the National Council on Independent Living, three nationally recognized disability rights groups;*
- *The National Council on Disability, an independent federal agency that was instrumental in drafting the legislation ultimately enacted as the ADA and has since monitored its implementation;*
- *The American Civil Liberties Union;*
- *The American Psychiatric Association and the National Alliance for the Mentally Ill, which filed a brief jointly;*
- *The Solicitor General of the United States and the U.S. Justice Department, in a "Brief for the United States";*
- *Former Attorney General Richard Thornburgh, who supervised the Justice Department as it developed regulations to implement and enforce the Americans with Disabilities Act, a critical element in this case; and*
- *Thirty national groups (plus seven Georgia groups) including: American Association of Retired Persons (AARP); American Association on Mental Retardation; American Network of Community Options and Resources; American Psychiatric Nurses Association; American Psychological Association; Arc of the United States; Autism Society of America; Brain Injury Association, Inc.; Catholic Charities, USA; Disability Rights Education and Defense Fund, Inc.; Epilepsy Foundation of America; Joseph P. Kennedy, Jr. Foundation; National Association for Rights Protection and Advocacy; National Association of Protection and Advocacy Systems; National Association of Social Workers; National Association of the Deaf; National Catholic Office for Persons with Disabilities; National Down Syndrome Congress; NISH (formerly National Industries for the Severely Handicapped); National Mental Health Association; Volunteers of America; and United Cerebral Palsy Associations, Inc.*

The National Catholic Office for Persons with Disabilities (NCPD) is known as "the voice of the Catholic Church in promoting the membership of people with disabilities in the church and society."[5] Mary Jane Owen, its executive director, issued the following statement: "NCPD could not avoid taking a position in this case which poses such serious threats, not only to those with mental retardation and mental illnesses, but to the millions of people who consider the ADA as important in guaranteeing those rights which we, as Americans, have always considered to be a part of our heritage. Its enactment followed years of effort on the part of the community in affirming their right to fulfill their God-given potential."[6]

◆ ◆ ◆ ◆

Why have so many powerful states and major organizations representing public entities joined with Georgia in attacking integrated services — the fundamental premise of the ADA —before the Supreme Court? Some of their key arguments, which are now being evaluated by the Supreme Court and which could prevail throughout the United States, are listed below, with a bit of context provided.

First, their briefs salute a state's right to avoid federal interference, a rationale familiar to African-Americans, women, and others who have badly needed - and rightfully obtained - help from the courts. Federal intervention became necessary because states historically denied persons who have disabilities the equal protection promised in our Constitution and finally assured them by the ADA.

In rejecting the States' argument, the U.S. Solicitor General's brief observes that "Legislation will be upheld as a valid exercise of Congress's power under Section 5 of the Fourteenth Amendment if there is a 'congruence and proportionality between the injury to be prevented or remedied and the means adopted to that end.' *City of Boerne* v. *Flores*, 521 U.S. 507, 520 (1997). The integration mandate of Title II readily satisfies that test."[7]

Second, even though the facts in this case are specifically about community-based care only when care in the community is appropriate, Georgia and

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Pulling the Plug on the ADA?

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its allies hope the Court will be put off by the (false) specter of *Olmstead v. L.C. and E.W.* leading to total deinstitutionalization and chaos.

Third, as noted, the ADA, its legislative history, and the Justice Department's implementing rules all specifically call for community care in integrated settings insofar as that would not have an undue financial impact on a public entity. In Olmstead, Georgia and its amicus briefs make unsubstantiated claims of imminent financial dislocation. But it is not at all clear that community care is more expensive, or even as expensive, as institutional care. In any event, this is a (theoretical) burden which the state, per ADA, could modulate.

Fourth, widespread stereotyping, sensationalism, and prejudice have fed regional NIMBY (not in my backyard) syndromes, fomenting irrational fears about including persons who have disabilities in their own communities. More politically powerful neighbors without disabilities have then put pressure on elected officials (and zoning officials) to protect their interests, as they see it, by excluding unwanted persons.

Fifth, vested interests often oppose diverting funds, jobs, and power from institutions into the community. Public officials may be loathe to buck institutions such as nursing homes and long-term care facilities which are a significant source of tax revenue and which help fund election campaigns.

Sixth, unions — traditional allies in civil rights struggles — are feeling and applying pressure to stem the flow of layoffs as institutions reduce their census or close their doors entirely.

AFSCME, the American Federation of State, County and Municipal Employees, joined numerous organizations in the Voice of the Retarded et al., amicus brief which supported the Court of Appeals ruling in favor of community care in this case!

> **"Too often," Georgia's own Governor Roy Barnes observed, "we institutionalize patients who pose no threat to society, who could be better served at a lower cost within the communities in which they live."**

However, their brief also emphasizes the need, in their view, to preserve the institutional-care option against an overemphasis on community-based care, even though community-based care is crucial to the integration mandate of the ADA: that is, the right of persons with disabilities to participate in programs and in our society alongside persons who do not have disabilities.

Seventh, and perhaps most chilling of all, is the argument advanced by the brief to the Supreme Court on behalf of states supporting Georgia, including Mississippi, Hawaii, South Carolina, Montana, Nevada, Wyoming, Tennessee, Texas, Colorado, Indiana, Massachusetts, Minnesota, and Washington. [Six of these states subsequently reconsidered and withdrew their names, leaving Colorado, Hawaii, Montana, Nevada, Tennessee, Texas, and Wyoming as Georgia's remaining allies.]

That brief proclaims that economies of scale will be difficult to achieve if patients are discharged. "If institutions begin to empty, the facility-based reimbursement schemes in place nationwide will be undermined because of the resultant diseconomies of scale. These institutions typically are reimbursed based on a daily bed rate, and to provide the best services must operate at capacity."[8]

◆ ◆ ◆ ◆

At the Supreme Court on April 21, the most important issue turned out to be none of the above. According to Georgetown University Law Professor Michael Gottesman, who argued L.C. and E.W.'s case before the Supreme Court, the concern uppermost in some Justices' minds was that a ruling in favor of Gottesman's clients would lead institutions to begin dumping patients onto the street.

The Supreme Court's concern about possible patient dumping is welcome, but it should not be used as a smokescreen. The Court, unfortunately, cannot unilaterally ensure that abuses do not occur. But if it chooses to, it can apply "strict scrutiny" to actions that might have a discriminatory impact upon persons with diagnoses of mental illness or mental retardation.

Applying its highest level of protection, or "strict scrutiny," would send a clear message to public entities that the Court means business in protecting the rights of this insular, oppressed, and politically powerless minority. Not only can the Court do so, but in light of its own criteria and in light of the passage of the ADA (embodying the voice of a coequal branch of government), it should feel morally obligated to do so.

Neither the ADA nor *Olmstead v. L.C. and E.W.* requires deinstitutionalization. What they do require, and what the Court should endorse with its full legal and moral authority, is the fundamental premise that persons with disabilities should not be needlessly forced into services or programs that are isolated and segregated from the rest of society.

The possibility that public entities may continue the historic abuse of persons

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with diagnoses of mental illness or mental retardation must not be used as a rationale for dealing a mortal wound to the ADA. Rather than per-petuate a system that is rank with abuse, the Court should exert its leadership to help create a legal, social, and political climate in which community-based services can and will succeed.

Applying "strict scrutiny" to actions negatively affecting persons who have diagnoses of mental illness or mental retardation would be an enormous step in that direction, one that only the Supreme Court can take. The *Olmstead v. L.C. and E.W.* case is the perfect opportunity.

The implications of an adverse decision by the Supreme Court in Olmstead are ugly: life unnecessarily locked inside institutions or state hospitals is degrading and often dangerous for persons already vulnerable to abuse and neglect. Less obvious consequences of an adverse ruling in Olmstead could haunt our society long after our current justices have retired.

Tragically, in the United States today jails and prisons are the emergency rooms and default treatment settings for hundreds of thousands of citizens with disabilities, many of them primarily 'guilty' of not having money, insurance or access to decent healthcare. Because of inadequate community-based services, police officers across our country are often forced to take persons who have a mental illness off frozen streets to jail. There are no integrated community treatment settings available to most of these Americans yet.

A Supreme Court decision supporting institutionalized, segregated services would send a message of approval to public entities across America that are inexcusably failing to provide persons with diagnoses of mental illness or mental retardation in crisis with community-based treatment and are instead routinely sending them to jail. A defeat on Olmstead would eviscerate the ADA. Our society, with the approval of our highest court, would occupy a squalid human rights niche in which the right to support and services in the most integrated setting would be replaced by isolation and segregation.

A bitter history has proven that laws and the courts cannot alone guarantee that adequate care will be provided, whether in institutions or in the community. But "care" that is only available behind bars -- in a "treatment" setting that stigmatizes and often traumatizes the recipient -- is beyond all national and international standards of law and decency.

The ADA was enacted by the United States Congress with overwhelming bipartisan support. If deconstruction of that landmark civil rights legislation were upheld in the Supreme Court, we would be rendered powerless to help a sibling, parent or child with a disability if he or she becomes subject to the tender mercies of an institutional administrator or public official who cares more about "economies of scale" than about human freedom and dignity. An assault of this magnitude on the civil rights of persons with disabilities threatens the freedom of all Americans.

Instead, let us hope that a majority of the Supreme Court, after considering the host of reasoned and passionate voices raised in support of Lois Curtis and Elaine Wilson—including a "Brief for the United States"—will affirm their constitutional and human rights. To do so will honor America's (and Georgia's) finest traditions.

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Jonathan D. Ezekiel is a writer and researcher based in Maryland. He is the author of "From Streets To Shelters To Jails" and "Covering the Newest ADA Decisions," both published in the Investigative Reporters and Editors (IRE) Journal, and the coauthor of Criminalizing the Seriously Mentally Ill: The Abuse of Jails as Mental Hospitals, a 1992 publication of NAMI and Public Citizen's Health Research Group.

References

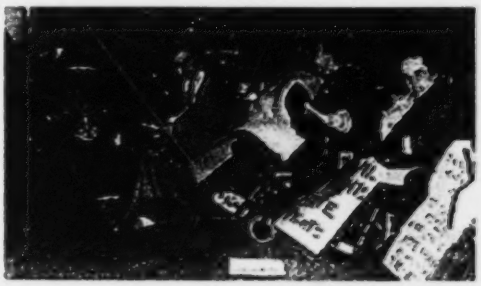
1. Atlanta's Legal Aid Society, at http://www.law.emory.edu/PI/ALAS/interesting.htm
2. The district court in Georgia "found that the annual cost to the State of providing community-based treatment to L.C. and E.W. - about $20,000 each - was not unreasonable in relation to the State's overall mental health budget, which was about $706.8 million in fiscal year 1998." U.S. Solicitor's Amicus Brief to the U.S. Supreme Court, *Olmstead v. L.C.*, Notes, p. 21., http://www.bazelon.org/olmstead.html
3. GA. Code Ann. 37-4-121 (Mitchie 1995), cited in U.S. Solicitor General's Amicus Brief to the U.S. Supreme Court, *Olmstead v. L.C.*, p.14., http://www.bazelon.org/olmstead.html
4. http://www.ganet.org/governor/spbudget.html
5. Brief for Amici Curiae American Association on Mental Retardation, et al., in Support of Respondents, Interests of the Amici Curiae, p. 13. http://www.bazelon.org/olmstead.html
6. Web Site of the National Catholic Disability Office, April 15, 1999. http://www.ncpd.org/OLMSTEAD.HTM
7. Amicus Curiae Brief for the United States, Seth P. Waxman, U.S. Solicitor General, et al., p. 19 at http://www.bazelon.org/olmstead.html
8. Amicus Curiae Brief of the States in Support of Petitioners to the U.S. Supreme Court, Frankie sue Del Papa, Attorney General of Nevada, et al, Olmstead v. L.C., p. 9.

BEST COPY AVAILABLE

On April 20, 1999 – the eve of the oral arguments before the U.S. Supreme Court in the case *Olmstead v. L.C. and E.W.* – approximately 150 tireless disability rights activists held an all night vigil on the sidewalk in front of the high court to demonstrate their support of the Americans with Disabilities Act.

L-R: Marcie Roth, Director of Governmental Affairs and Public Policy, TASH; Lois Curtis; Linda Anthony, Executive Director, PA Coalition of Citizens with Disabilities; and Elaine Wilson. Lois and Elaine are the named plaintiffs in the original lawsuit.

The night-long vigil was followed by a groundswell of additional supporters that arrived at the Supreme Court on the day of the oral arguments.



Rights activists prepare for a night on the not-too-warm sidewalk near the Supreme Court building.

The Serena Merck Memorial Award
for Innovation and Dedication in Practice

Purpose of the Award The Serena Merck Memorial Award is given annually to an exceptional individual who has demonstrated long-term, selfless dedication and compassion in the care or service to children who have retardation and significant mental health problems. Mrs. Merck recognized the critical importance of what quality day-to-day care provided by committed individuals can make to children with cognitive and behavioral disabilities. The John Merck Fund has established this major, national award to honor her long-standing commitment to this field, and to call attention to the invaluable role caring individuals play in it.

Criteria for Selection of the Awardee Prospective awardees should meet one of the following categories: (1) Provides, as an employee or volunteer, services for children who have mental retardation and significant mental health problems. (2) Demonstrates long-standing commitment and innovative care of this population which has positively affected their quality of life and/or life opportunities.

Submission Guidelines Organizational entities may nominate prospective awardees. One nomination per organization is permitted, although multi-service organizations may submit one nomination from more than one service unit. No self-nominations are acceptable. Only organizations serving children with mental retardation and significant mental health problems are eligible to nominate an individual. A 500-word summary of the reason the candidate is nominated, length of service in the field, and a description of the person's impact on children with mental retardation and significant mental health problems is required. At least two, but no more than five, accompanying letters of reference from individuals well qualified to evaluate the candidate's suitability for the award should be provided.

Nominations should be mailed before September 15, 1999, to:
Mr. Frank Hatch, The John Merck Fund, 11 Beacon Street, Suite 1230, Boston, MA 02108

Award A $5,000 cash award and plaque will be presented to the awardee at the 16th Annual National Association for the Dually Diagnosed (NADD) Conference held November 10–13, 1999, in Niagara Falls, Canada. The awardee's travel expenses to the conference will also be covered.

INTERNATIONAL DISCUSSION GROUP ON TRANSFORMING THE SERVICE DELIVERY SYSTEM

BY BRIAN SALISBURY AND STEVE DOWSON

An international e-mail discussion group began approximately three years ago for the purpose of focusing on new approaches for allocating public money and providing planning assistance which will (or could) enable people with disabilities to obtain the community services and supports they require to participate as full citizens, without losing control of their lives.

To date, discussion topics have included:

- The advantages and limitations of different fiscal mechanisms such as individualized funding and direct payments, and their advantages and limitations;
- Various forms of technical planning support, such as service/support brokerage, which people sometimes require in order to identify and meet their community living needs, including managing their supports;
- The roles and rightful powers of the various actors in a demand driven system, including people with disabilities, family members and advocates, government and state agencies, service providers, professionals, brokers and other advisers;

In the context of this group's discussions, support for the principle of transferring power is taken as a given.

- Identifying the appropriate balance between the freedom of the individual who requires support to achieve his/her own desired future, and the duty of the State to ensure that public funds are used properly;
- Strategies that will lead to the broader acceptance and implementation of these alternative approaches for allocating financial and planning resources; and
- The ways in which these new funding and personal planning systems may be obstructed or perverted by vested interests, and strategies for avoiding or countering such problems.

By the nature of these topics, much of the discussion is fairly technical and abstract. However, the dialogue is generally kept "on the ground" by contributors who can speak from their experience of being on the receiving end of individualized funding arrangements, or working to develop real alternatives to global/block funding and case management or service coordination.

Please note that although contributions to the list frequently refer to issues such as inclusion, self-determination and self-advocacy, this forum is not intended to be a place for general discussion of these issues. While the shift of power to the people who need financial support from the State certainly presents many practical difficulties, on this list, support for the principle of transferring power is taken as a given.

Currently there are over 175 participants from 10 different countries. People are asked to share their perspectives with the entire group as much as

possible, rather than engaging in private discussions. Additionally, participants are encouraged to inform self-advocates and family members about the discussion group since these constituents are critical to the process of transforming the service delivery system.

This description of the discussion group also appears in the Discussion Section on the Individualized Funding Home Page. The page is an outgrowth of this e-mail discussion group. The URL is: http://members.home.net/bsalisbury/

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The discussion group is operated and moderated by Brian Salisbury in Canada, assisted by Steve Dowson in the United Kingdom. To join the list, please contact Brian Salisbury at <bsalisbury@home.com>

Brian is a Contract Instructor in the Community Support Worker Program at Kwantlen University College in Langley, British Columbia. A former service broker, he has written and consulted extensively on individualized funding and service brokerage since 1984.

A "NEW" DR. DEATH AT PRINCETON

BY MARY JANE OWEN

We wish to thank the author and the National Catholic Office for Persons with Disabilities (NCPD), P.O.Box 29113, Washington, D.C. 20017, Phone: (202) 529-2933, for granting permission to reprint the following article.

It would seem the disability community should be in the lead as thoughtful Americans learn more about the appointment of Australia's "most notorious messenger of death," to the DeCamp Professorship of Bioethics at Princeton's Center for Human Values. This so-called bioethicist denies the essential worth of human life, asserting, "Killing a defective infant is not morally equivalent to killing a person." He considers that such "nonpersons" (a designation which is also applied to adults) are living lives not worthy of life and, thus, can best be eliminated as useless "burdens" to society.

His appearances in Europe and Asia to speak about the positive value of eugenics, euthanasia and his denial of the inherent dignity or value of babies, children, the elderly and people with disabilities, have resulted in dramatic protests by disability advocates and others. There have been cancellations of his speechs in which he planned to spread his theories because people in wheelchairs chained themselves to the doors of the lecture halls where he was scheduled to disperse his dreadfully negative stereotypes. Upon occasion, he has been shouted down. In Germany, the disability community likened his solutions to the "challenges" of disabilities to those of the Nazis. Certainly he approves of the same "final solution."

But in the United States Singer is an unfamiliar figure. Those familiar with his name are involved with the animal rights movement. And the reason for their interest is his repeated assertions that the life of a young pig is more worthy than that of a child with disabilities since, within his frame of reference, the pig is capable of more pleasure than is possible for a person with a significant disability.

"Mr. Singer does not tell us who, in his ideal world where only the worthy will live, would make such an 'obviously correct' judgement, but presumably we can be grateful he was not the attending physician when Christopher Reeve was brought into the emergency room, or the obstetrician who delivered Helen Keller, or the doctor who diagnosed Franklin Roosevelt's polio."

Princeton alleges in defense of its appointment of Singer that the Australian is no activist, just a scholar dedicated to discussing theoretical solutions. But Singer himself acknowledges he seeks to replace the Judeo-Christian ethic with "new commandments," based upon a utilitarian model. He promotes disdain of traditional spiritual concerns.

This newest Dr. Death, in an interview with Frederick Kunkie in the July 20th *Star Ledger* said, "I'm very excited. I'm looking forward to being at Princeton . . . . To having great, stimulating colleagues to work with and excellent students." He anticipates that Americans will be more receptive and less inclined to find his views offensive than people with disabilities in Europe and Asia.

British philosophy professor Davis S. Oderberg tried to awaken us to the dangers [of Dr. Singer's theories] in a June 30th (1998) warning in the *Washington Times*: "Consider the evidence. Professor Singer has said in print, time and again, that babies and infants with disabilities have no right to life. Indeed, only human beings with 'lives worth living' are worthy of serious protections, and even they have no right to life as such, since talk of rights is, he says, 'a convenient political shorthand' for 'the era of thirty second TV news clips.' As he argues in his notorious book, Should This Baby Live, if a human being has a life not worth living, it can be permissible, and even sometimes a duty, to kill such a one." Oderberg notes, "Newborn babies have, in his own explicit and unbelievable analogy, the same moral value as snails."

In an August 3rd *Wall Street Journal* editorial, Terry Golway quotes from Singer's book, Practical Ethics: "Although people sometimes talk as if we should never judge a human life as not worth living, there are times when such a judgement is obviously correct." Golway then commented, "Mr. Singer does not tell us who, in his ideal world where only the worthy will live, would make such an 'obviously correct' judgement, but presumably we can be grateful he was not the attending

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A "NEW" DR. DEATH AT PRINCETON

Continued from page 14

physician when Christopher Reeve was brought into the emergency room or the obstetrician who delivered Helen Keller or the doctor who diagnosed Franklin Roosevelt's polio."

Professor George Kateb of Princeton has sought to justify both Singer and his appointment to a chair on human values, accusing those who raise questions about the advisability of this action of not doing "their homework." Golway replied in a September 12 essay for America, "Professor Kateb is right in saying these quotes (Used in an earlier article critical of Princeton's choice) do not do justice to these views. You have to read the book (Practical Ethics) to get the full effect."

Singer's lack of sensitivity about the complexity of human interaction is revealed in his rhetoric. Obviously, he has never shared the joy and wisdom to be gleaned within a population he targets for "justified" extinction: people with mental retardation. Probably he has never celebrated the personal victories of adults as we learn new ways of compensating for lost functions. The American belief that overcoming tough challenges reveals the most noble of human traits has persisted through the years. Obviously such a concept has no place in this Australian's mind-set.

If you find Dr. Singer's appointment inappropriate, please write of your concerns to the Center for Human Values, Princeton University, 304 Louis M.A., Princeton, NJ 08544. They have prepared a form letter response which might make a nice souvenir to share at your next disability rights gathering.

JUSTIN DART RESPONDS TO PRINCETON ON SINGER'S "ETHICS"

Following is the text of a letter written April 14, 1999 by Justice for All's Presidential Medal of Freedom recipient and TASH lifetime member Justin Dart to the Trustees of the Center for Human Values, Princeton University, concerning the appointment of Peter Singer.

Princeton University's Center for Human Values recently employed Dr. Peter Singer as a professor of Bioethics. Dr. Singer states "Killing a disabled infant is not morally equivalent to killing a person. Very often it is not wrong at all."

In the context of [Jack] Kervorkian's well-publicized assertion that many people with disabilities are better off dead, I am horrified that the prestige of Princeton University is now supporting a man who advocates killing babies with disabilities. This message will go out through the media to pollute the thinking of every person, every family member, every government official, every medical person, every educator, every potential employer, who will make decisions impacting the lives of people with disabilities.

[Some may ask] "Why should I sacrifice extra time or resources to support these semi-humans, many of whom are better off dead?" Equally horrible, the prestige of Princeton will seem to condone the murder of babies with disabilities in the nations where this barbarian practice still exists.

My granddaughter, Dana Washington, was born with a seemingly hopeless medical situation. The doctors said, "she can not live. If she does live, she will not be fully human -- let her go." Her parents insisted on Hail Mary procedures. Now she is an "A" student in high school, a cheerleader, a journalist, a ballerina, and a civil rights leader.

It is impossible to predict the miracles of science. It is impossible to justify any kind of science and utilitarianism that is not dedicated totally to the sacred value of the continuum of human life: individual, family, society, universe - starting always with the individual.

I respectfully implore the Trustees of the Center for Human Values to utilize its enormous prestige for the value of human life.

Justin Dart

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If you agree with Mr. Dart's position, we urge you to immediately write to each of the following:

Harold T. Shapiro, Ph.D.
President of Princeton University and
Trustee Ex-Officio
Phone: 609-258-6100
Fax: 609-258-1615
Address: Office of the President
One Nassau Hall
Princeton, NJ. 08540
Email:hts@Princeton.edu

Christine Todd Whitman, B.A.
Princeton Trustee Ex-Officio
Governor of the State of New Jersey
125 West State Street
PO Box 001
Trenton, New Jersey 08625-0001
Phone: (609) 292-6000
TDD: (609) 777-1292
Send the Govenor electronic mail from the website:
www.state.nj.us/governor/govmail.htm

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Lane Education Service District - Eugene, Oregon **invites applications for the following positions:**

Supervisor, Life Skills Education Program
Qualifications:
1. Master's Degree required, with preference of focus on students with moderate to significant disabilities.
2. Qualify for Oregon teaching license with special education endorsements.
3. Qualify for Oregon administrative license.
4. Five (5) years successful experience as licensed staff member in public schools, including 2 years as an administrator, with preference given to experience with students who have moderate to significant disabilities.
5. Experience in the implementation of state and federal laws regarding the education and required related services for students with disabilities, as well as knowledge of budgetary requirements.

Teacher, Life Skills Education Program
Qualifications:
1. Qualify for Oregon Handicapped Learner License or a Severely Handicapped Learner's License.
2. Teaching experience with MSMR students is preferred.

Consultant-Autism
Qualifications:
1. Master's Degree in education.
2. Qualify for Oregon License with an Oregon Handicapped Learner Endorsement, or Severely Handicapped Learner Endorsement.
3. Demonstrated successful experience working with students with autism and students with challenging behaviors.
4. Experience in developing behavior programs based on positive, non-aversive approaches. Ability to relate and communicate effectively with families of students with special needs and educational staff.

Positions close: May 28, 1999

Lane ESD is located in Eugene, OR, a city of 125,000 situated at the southern end of the Willamette Valley about 100 miles south of Portland. Lane County's 4,500 square miles extends from the Pacific Coast to the Cascade Mountains. From Eugene, coastal beaches are one hour away to the west and snow skiing is one and one half hours to the east.

Eugene and its surroundings provide an ideal living environment, rated one of the best in the United States. Outdoor and cultural activities abound. Eugene is home to the University of Oregon and Lane Community College. Education is a high priority for the citizens of Lane County.

Apply to: Human Resources, Lane Education Service District, P.O. Box 2680, 1200 Highway 99N, Eugene, OR 97402, 541-461-8202

An official Lane Education Service District application form must be submitted in order to be considered for this position.

The Importance of Arts Education for All Students

BY FLORENCE AVERSA

The following is a rationale for why all children need the arts and why children with special needs, in particular, benefit so greatly from these programs. Why, exactly, are the arts so important to children?

The most basic reason that children — in fact all individuals — need the arts is that **the arts are valuable in and of themselves**. They are a source of human insight about the world and ourselves. The arts connect us to the past, and help us imagine new possibilities for the future. They give us a universal language through which we can express our emotions, our hopes, and our dreams. The arts are a channel for understanding and appreciating others, but also provide a way of knowing and defining who we are.

All children need the arts because we believe every child, with or without a disability, is a natural artist. Give most children a brush and paint, they jump right in, sometimes literally. Put on some lively music, there's an instant response. Children are excited about art, they're enthusiastic, and instantly engaged. For the most part, children don't have the inhibitions adults often experience when faced with an artistic challenge such as performing on stage. To children, the arts are fun, and children are naturals at it. From a child's point of view the pictures they draw, the songs they sing, the dances they perform, and the stories they act out are as important accomplishments as anything else they do in school.

Arts-integrated inclusion programs give everyone the chance to join in, communicate, leave their mark, and make their statements by focusing on opportunities and not obstacles.

All children need the arts because the arts engage children at their most personal level—that of imagination. In this arena, children have the unique power of creating and arranging a world of their own choosing, whether it be filled with family and friends, cartoon characters, ferocious creatures, or the latest superheroes. Using art forms, the child is empowered, the creator and mover of all that exists and happens. Whether the child is creating this vision on paper with drawings or creating an actual environment with toys, clay, blocks, or paraphernalia, for a time it becomes a magic "other place," with its own rules and order — and the child is the ruler of this domain.

How does this empowerment through imagination, the arts and the desire to create translate into the often mundane world of curriculum that we as educators inhabit? It is one of our most powerful tools. **An arts-integrated curriculum provides another key to learning.** The real world we seek to teach about — with its amazing geography, colorful history, and its awe-inspiring scientific frontiers offering a host of real life heroes past and present — opens itself up for exploration and discovery. When children are acting out scenes from history, singing songs about the states, writing a script for a puppet show, or painting a mural about the space program, they are taking new information and making it their own through the arts.

In the midst of the fun, thinking skills of the highest order routinely come into play. Making decisions and choices, creating an order, engaging in problem-solving, experimenting, predicting and discovering outcomes — not to mention positive social interactions — this is learning at its best. And most important, these are the precise skills children will need to succeed later in life.

How do the arts particularly benefit the child with special needs? Simply stated, **the arts provide an arena where every child can participate.** At the O'Hearn School in Boston, no one is left on the sidelines, so we have wheelchairs in dance class, children with autism taking piano lessons, and group painting activities where children help each other. When we have a show (and we have lots of them), everyone is included, doing the most they can. Uncovering hidden talents is the job of every arts teacher, so the focus is always, "What can you do? How far can you go? How high can you fly?" and then creating plenty of opportunities for children to shine.
In his writings on multiple intelligences, Howard Gardner identified 7

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The Importance of Arts Education

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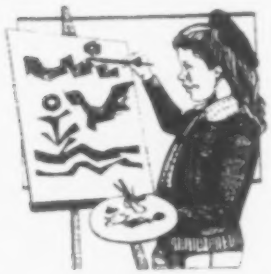
types of intelligence that need development in every young person. Still other types of intelligence have been identified. In many schools, most of the day's lessons address only two — the linguistic and logical/ mathematics. But children also need to develop musical, spatial, bodily/kinesthetic, interpersonal, intrapersonal, and emotional intelligences. For a child who has difficulty with academics, the arts provide other ways to learn by addressing those other intelligences. For, unlike some areas, in the arts there is no single right answer, and thus there are limitless possibilities for success.

For children with special needs, the arts also provide a strong motivation to attempt more difficult things. They will push their verbal and motor skills and typically increase social interactions with classmates. They become totally involved and enjoy the exhilaration of having created something personal — a picture, a dance, a clay figure, or a role in a play. Parents become involved, and get to see their child, on stage perhaps, and in a whole new light: happy, successful, proud. Studies have shown that the appeal of the arts is so strong that high school students involved in arts programs have higher motivation to keep going to school, their drop out rates are lower, and greater numbers of students graduate.

The arts are the most powerful means of communicating our innermost being.

Children, in fact all people with disabilities, have an especially compelling need to express themselves, for their voices are seldom heard. Assumptions are often made about what they can't do, while they yearn for an opportunity to join in, communicate, leave their mark, and make their statements. Arts-integrated inclusion programs give everyone that chance by focusing on opportunities and not obstacles. A disability does not necessarily disable the creative process, but it often requires using special tools, modifying the environment, or adapting



instructional methods. It is up to us as educators to find the right tools, unlock the doors, and to empower that creativity in every one of us.

Florence Aversa has taught in the Boston Public Schools for over 30 years. From a Liberal Arts education at Boston University and the Sorbonne in Paris, Ms. Aversa added a broad arts repertoire to her professional and personal development over the years, studying at Massachusetts College of Art, the Museum of Fine Arts, and at other world-renowned academic and artistic institutions.

Integrating her background as a classroom teacher and school librarian with her diverse experience in the arts, she currently teaches visual arts, music, and theater at the Patrick O'Hearn School in Boston. Ms. Aversa has been awarded numerous grants and awards for programs that employ the arts to illuminate the general curriculum, to promote literacy, and to develop a sense of positive personal identity in students.

The Patrick O'Hearn School is an inner-city, full-inclusion school where children with moderate—and significant special needs learn in the same classrooms as regular ed students. Featured on NBC's Dateline for its successful inclusion programs, the O'Hearn provides all its students, from Pre-K to Grade 5, instruction in dance, music, drama, and visual arts throughout the school year.

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Betty Bollier, Diagnostic Center Southern California, 4339 State University Drive, Los Angeles, CA 90032; Phone: 323-222-8090

Employment for anyone, anywhere, anytime

Creating New Employment Options Through Supported Employment & Supported Self-Employment

BY DAVID HAMMIS AND CARY GRIFFIN

The Fire and Energy of Supported Employment and Employment Consultants

Supported employment is a raging fire, burning bright across the world. We have felt it now for 20 years, as it's burned a passion into our souls to strive for employment for anyone, anywhere, anytime. It still lights up our imaginations with promises and potentials unmet. We have seen it in the eyes of the best employment consultants. It is the intuitive energy of listening to someone during a Personal Futures or Vocational Profile process and really understanding the work and employment dreams of another person.

Supported employment is networking, marketing, and negotiating with the business world for profitable and exciting employment partnerships. Supported employment is searching the workplace for the clues of future job carving possibilities and ideas. It is engaging workers, co-workers and supervisors to be their best and the timing of knowing when to assist and when to create time and space for natural events and relationships to occur.

Supported Employment in the Global Economy of the 21st Century

Supported employment under its momentum and presence will soon move into the 21st century. Without a doubt, supported employment continues to validate the beliefs and dreams it was founded on. The heroes of supported employment are the 150,000+ employees, employers, and employment consultants around the nation creating new social and cultural realities barely imagined only a decade ago. The challenge is, as it has been from the beginning, to raise our expectations beyond the word "employment."

As we approach the thresholds of the trends and complexities of the business world, new words are starting to be added to our vocabulary. Words like profit; partnerships; corporations; s-corporations; limited liability partnerships; limited liability companies; entrepreneurial; leveraging resources; small business; women-owned small business; minority-owned small business; employee-owned businesses; corporate culture; re-engineering; downsizing; rightsizing; owners; and shareholders. As we add these words from the business world to our vocabularies, do we really hear them? Perhaps the question is how do we blend the fire and energy of our brightest and most creative employment consultants with the challenges of the next century? What tools and cultures need to be developed and promoted as we push the boundaries of our existing approaches to their limits? Where are we going? How do we build on and add to our current supported employment strengths?

> **"The challenge is, as it has been from the beginning, to raise our expectations beyond the word 'employment'."**

Supported Self-Employment, Business Partnerships, and Ownership

Moving supported employment into the next century requires new options, new supported employment cultures, and new tools for employment consultants. Fortunately, the next steps are here today. They have been here for years. Just as supported employment started from the creativity and visions of excellence, the 21st century tools for new supported employment futures are developing today as employment consultants embrace the business world and its array of work and employment options. The only real barriers seem to be in our beliefs and expectations. Employers are interested in hiring employees who own substantial employment-related resources, forming limited partnerships, and supporting sole proprietorships with people of similar interests and dreams. The business world has been and is ready to do business. How do we know this? We asked.

Do you know that small business is the fastest growing segment of the business sector today? Is this a business trend that people engaged in the work of employment should be aware of? We need to believe that all of the options in the business world are possible for people with disabilities, and then act on those beliefs. Acting on those beliefs makes it possible to achieve employment for anyone. Taking action opens new worlds and options for people to become partners in businesses; sole proprietors; and employees with ownership of vital business resources, through creating paid work

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Employment for anyone, anywhere, anytime

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and profits from the needs of the business and economic culture in each community. If this can happen, as it has repeatedly in small, remote communities (such as Plains, Montana: population 1,200; Red Lodge, Montana: population 2,300; Alamosa, Colorado: population 10,000; Sterling, Colorado: population 5,400), it can happen where you live.

Employment for anyone, anywhere, anytime

Recently in a small rural town in Montana, a "challenging" person who was identified as having multiple and significant disabilities, shared with us his work dreams. The place he identified for his work dreams was a local "Nature Center." He took us on a tour and clearly demonstrated the interest and relationships he had already developed there. In attempting to develop a job here, multiple objections were offered from the manager, including the lack of funding for new employees. The manager would agree to any volunteer help, but "had no money" for employees.

The early promises and potentials of supported employment have become the reality for thousands of people, yet millions of people wait for similar futures in workshops, day activity centers, and institutions.

Acting on the belief that it is possible to create employment for anyone, a business plan for a sole proprietorship in retail sales of items related to the Nature Center was developed and given to the manager. The plan proposed the operation of a sales business at the Nature Center in return for 10% of the profits. The manager reviewed and assisted in refining the business plan and then submitted it to the Board of Directors for approval. The business is owned by the person, and we were able to clearly "create" a work outcome following our beliefs of employment for anyone, anywhere, anytime.

Another example involves a young man in another Montana rural town, where an employer was approached to develop a position as an entry level mechanic assistant. The employer did not have an adequate cash flow to hire him. A limited partnership proposal was written to utilize some funds from a Social Security Plan for Achieving Self Support (PASS), and to become a part owner of a small segment of the business. The wealth of knowledge of the business world came into play again, as the owner advised, amended, and assisted with creating an entirely new proposal for a sole proprietorship for the young man that would work based on a $28.00 per hour contracted rate for the individual's new small business. The proposal included a 25% consignment fee for the use of space at the principle owner's building, and a clear method for sharing of customers and workloads. The Business Plan and PASS have been approved, and an absolute "no" from a potential employer was turned into a mutually profitable sole proprietorship and partnership.

What Comes After What Comes Next

For the past ten years, the field has struggled with determining what jobs people can do; what jobs people should do; and what jobs are available. The discussions and hard work are far too often focused on organizational resources, restrictive or limited policy, and agency convenience. These are the wrong concerns and mindset. The employment arena is not a finite resource, although the human services perspective has ascribed this characteristic to it. Neither is employment development a passive activity. Employment is created through vigorous and relentless creativity, invention, partnership, collaboration, and hard work. Even in the smallest communities, in the most rural corners of the world, we are finding, as colleague Roger Shelley says, that there may not be a lot of jobs, but there sure is a lot of work. Skilled consumers, families, and personnel will exploit the reality of market expansion through tenacity and risk-taking. There is a conscious choice to be made by each of us: have the world act upon us, or act upon the world.

Making employment happen requires a drastic change in daily activities.

- **First, quit doing things that do not lead to employment** (Do endless meetings come to mind? How about work readiness training that has proven to be a dead-end towards community employment?).
- **Second, ask business people how they got into business and what they need to stay in business.** Act to help them find and hire people.
- **Third, listen to the job seeker.** What do they want to do and how close can you get by enlisting employers, friends, family?
- **Fourth, stop making assumptions based upon behaviors and motivations witnessed in boring, repetitive, segregated settings.** Stop wasting time and money on interest inventories and standardized testing. Instead, develop situational assessments and job analyses that give real information with environmental relevance.
- **Fifth, listen to yourself.** Are you in this job for something to do, or to do something? For most people served in community rehabilitation there is no Plan B. Most people are stuck in dead-end day programs, so

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Employment for anyone, anywhere, anytime

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what exactly is the big risk in trying a job, even one you personally may believe to be "unrealistic?" Twenty years ago it was unrealistic for people with significant disabilities to work in any community job. Today we know that to be a terrible assumption. Do not become the people that the next generation frowns upon for being so "backwards" in its attitudes. All of the pieces to create quality community employment exist now.

...employment development [is not] a passive activity. Employment is created through vigorous and relentless creativity, invention, partnership, collaboration, and hard work.

The early promises and potentials of supported employment have become the reality for thousands of people, yet millions of people wait for similar futures in workshops, day activity centers, and institutions. There are still so many supported employment promises unmet. It is time to take the next quantum leap into our shared futures with the business worlds around us, building on the employment consultant's energy, dreams and skills, and create employment for anyone, anywhere, anytime.

David Hammis and Cary Griffin work with the Rural Institute, University of Montana, 52 Corbin Hall, Missoula, MT 59812. Phone: (406) 243-2454; Fax: (406) 243-4730.

David can be reached by e-mail at dhammis@selway.umt.edu. Cary's e-mail address is cgriffin@selway.umt.edu.

From the Executive Director

Continued from page 3

chapter. Two chapters, New England and Virginia have expressed interest in working with us on this.

International Self Determination Conference: TASH is working with a group of people from the US, Canada and the UK to plan an international conference on self-determination for the summer of 2000. Current plans are to coordinate this conference with the International Association for the Scientific Study of Intellectual Disability's (IASSID's) Congress planned for August 1-6 in Seattle.

Olmstead Case: The Olmstead case is an important case which was heard by the U.S. Supreme Court on April 21st. The case will determine whether people have a right, under the Americans with Disabilities Act, to live and receive supports in the community. Steve Gold wrote an Amicus Brief in support of this right for TASH, ADAPT, and NCIL. Marcie Roth, TASH's Director of Governmental Affairs and Public Policy spearheaded the planning for an overnight vigil the evening of Tuesday April 20th through the 21st, the day the Supreme Court heard the case. About one hundred and fifty disability advocates from across the country spent the night in front of the steps of the Supreme Court Building, making sure the voices of the disability community were heard on this important issue. (See related story, p. 8)

OSERS Grant: TASH and the National Association of State Boards of Education are developing a response to a Request for Proposals from the Office of Special Education and Rehabilitative Services. The proposal is for a national center to provide leadership in improving results for students with disabilities through access to the general education curriculum. Supporting organizations include the American Association of Colleges of Teacher Educators, Arc-U.S., The Beach Center, the Center for Law and Education, The Council of Administrators of Special Education, the Council for Exceptional Children, Fiesta Educativa, The National Association of Protection and Advocacy Systems, The National Association of School Psychologists, the National Center for Educational Restructuring and Inclusion, The National Down Syndrome Congress, the National Councils on Independent Living, PEAK Parent Center, and many others. The work of the center will focus on three broad areas:

- Compiling and synthesizing relevant research on preferred or promising practices that affect access to the general education curriculum and for achieving improved results.

- Evaluating current state and local policy regarding access to the general curriculum for students with disabilities. This includes an examination of the linkages among standards, assessments, accessible curriculum and results, and other educational reform initiatives that affect the general education curriculum.

- Developing partnerships with leaders and key stakeholders in special and regular education, developing informational materials, and implementing a range of dissemination activities with national special and regular education technical assistance providers to encourage the adoption of effective practices and policies.

If funded, Dr. Richard Villa will serve as Project Director. TASH will act as fiscal agent and provide the administrative umbrella.

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trains teachers to serve the needs of pupils with significant disabilities. Emphasis on data-based, systematic instruction referenced to the requirements of natural school and community settings. M.Ed. degree plus initial teacher certification possible.

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EXECUTIVE DIRECTOR

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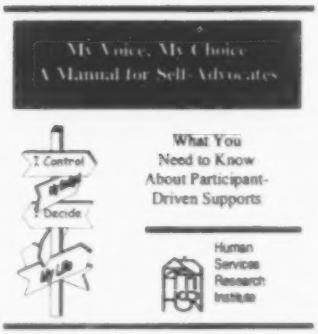
Self Determination and Participant-Driven Supports

My Voice, My Choice: A Manual for Self-Advocates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What You Need to Know About Participant-Driven Supports
Human Services Research Institute

By John Agosta, Kerri Melda & Cathy Terrill

Due to funding limitations and service wait lists the developmental disabilities field is changing. Adding to the changes are evolving service practices, including commitments to self-determination, community integration and participant-driven supports.

Whatever the changes in your state, self-advocates must influence events. *My Voice, My Choice* is a must-have curriculum. Use this manual to provide self-advocates with the information they need to help shape the service system. Use it also with family members, board members and service staff.

Eight chapters include basic definitions and concepts about how service systems work, along with explanations of participant-driven supports and managed care. Strategies to analyze a state system and influence change are also covered.

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TASH CHAPTER CORNER

BY DONNA GILLES AND TIM KNOSTER
TASH Executive Board Members

One of TASH's current priorities is to provide support to Chapters that are interested in further communicating their activities and local agendas. One strategy along these lines is to highlight TASH Chapter information in the Newsletter. Specifically, we plan to revitalize what was previously known as the "Chapter News" column on a periodic basis. The Chapter Corner will serve this purpose in this and future editions of TASH's Newsletter. While Chapter Presidents will receive periodic correspondence soliciting information, all TASH Chapter members are encouraged to submit information for consideration for inclusion in the Chapter Corner. Relevant Chapter News is to be submitted to Priscilla Newton.

We are both pleased and excited to highlight the following information from four TASH Chapters. Together, through our international and local efforts, we will continue to make strides towards realization of our shared TASH vision and mission.

Virginia TASH

Virginia TASH has collaborated with the Commonwealth Coalition for Community (CCC), another kindred grassroots advocacy group, and continues to bolster efforts to improve services provided by the New River Valley Community Services Board. The CCC and VA TASH are collaborating in an effort to see services become consumer-driven and supports offered in the individual's home and community of choice. In support of these activities, VA TASH is striving for positive results in federal legislation. VA TASH continues to advocate regarding IDEA '97 implementation and joins International TASH and others to defend against attacks that threaten what VA TASH believes to be a good law. VA TASH has worked in support of MiCASSA and plans on this being an ongoing area of focus.

Missouri TASH

The MO-TASH conference, "Take Risks . . . Ride the River: Building Opportunities for People with Disabilities and Their Families," held on February 18 & 19, was built on a theme that embraces TASH values. To live a quality life filled with family, friends, learning adventure and rich participation in everything around us involves taking risks. These risks are not only on the part of people with disabilities, but on the part of all of those around them - professionals, friends, and family. It's risky to learn new things, to try new things, to change. Essentially, navigating the "river of life" (at the risk of being a little too metaphorical) is just plain risky. Risks not taken are missed opportunities. This is what the MO-TASH conference was all about and many of the people who attended relished in this orientation.

The evaluations turned in included such comments as the following: "People with disabilities were wholly welcome!"; "(I got a) sense of what is ahead."; "Rud Turnbull was excellent!; We must discuss politics/law."; "The keynote speakers were overwhelming and interesting."; "(What I liked most) about the conference was "camaraderie."; "New faces, nice crowd"; "(I learned that) more people with disabilities are out there in the working force."; "Down to earth topics and discussion (is what I likes most.)"; "The topics of the breakout sessions were so good, it was hard to choose which one to go to." Other evaluations reflected that TASH as an organization is not being totally clear about what its values and its mission are. Some additional comments may encourage us all to be more clear, more loud, and more emphatic about who TASH is and what it believes.

> " . . . it's that there are some aspects of a person's life that we have no right to compromise. We cannot negotiate the size of an institution: no one should live in one. We cannot function on a committee to determine who does and who does not get medical treatment: everyone does. We cannot debate who should get an integrated education: all must . . ."
>
> *Lou Brown*

MO-TASH is an organization that advocates for the full participation of people in all aspects of their lives. Institutions and segregated settings are not visions of full participation. MO-TASH recognizes that people, professionals and people with disabilities alike, are in these settings often because they are trying to make a difference from the inside, or because they have no assistance to support their choice to live, work, and/or play in an inclusive community. MO-TASH's role as an organization and as its membership is to

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TASH Chapter Corner

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expect and push for supports for people who make real, informed choices to take the risks and to ride that river.

Lou Brown, one of the founders of TASH said it best when he wrote, "*. . . it's that there are some aspects of a person's life that we have no right to compromise. We cannot negotiate the size of an institution: No one should live in one. We cannot function on a committee to determine who does and who does not get medical treatment: everyone does. We cannot debate who should get an integrated education: all must. Just because we are overwhelmed, frustrated, and at a loss for something to do, we cannot tolerate shocks, slaps, pinches, or any other obnoxious violation of dignity. Let the moderates, compromisers, and data worshipers go elsewhere. Let the people of TASH be value-based, unbending, tough, aggressive, assertive, graceful, compassionate, and effective.*" (From "Who Are They and What Do They Want? An Essay on TASH").

Texas TASH

Texas TASH is addressing a number of important issues, not least of which are:

a) Establishment of an "action-oriented" executive board. We are moving beyond just holding meetings and discussing state-level problems; and

b) Participating in a functional-contextual assessment and portfolio development training project in partnership with LRConsulting, Family-to-Family Network and Sam Houston State University. Texas TASH is hosting Saturday training sessions around the state for parents and educators on this very important topic as it relates to the IDEA Amendments of 1997 and Best Practices. Several of Texas TASH's executive board members participated in Trainer-of-Trainer sessions, so that Texas TASH can increase the availability of this workshop. Each person who attends pays a registration fee of $30 and receives the resource MaxiM: Linking Functional-Contextual Assessment with the Instructional Process, along with supplemental handouts and a full day of interactive training. Participants also have the opportunity to browse through several portfolio developed by parents and educators on students with different types of disabilities; Texas TASH is targeting parent support groups to host these workshops. For more information, contact Mary Fitzgerald, Chapter President of Texas TASH at maryfitzlrc@earthlink.net.

Indiana TASH

Indiana (IN-TASH) has one top priority this year. We are focusing on legislative issues. Our board is following the work of the Indiana General Assembly and the US Congress. Our meetings are working meetings where we share information and decide on a course of action to follow. This usually involves a letter writing or phone calling campaign to key individuals expressing our (IN-TASH) views regarding the legislation or policy issue in question.

NEW Video!

A Landmark Video About a Landmark Case

NEW Video!

The History & Legacy of the Pennhurst Order as Given by Judge Raymond J. Broderick

One of the country's oldest and largest state institutions for people with disabilities was located outside of Philadelphia, Pennsylvania. After more than three decades of demonstrations, press exposes and legal battles, Pennhurst State Institution was finally closed as the result of an Order to place people in the community.

The history of this landmark event is captured in a new half hour video. Judge Raymond J. Broderick, the judge who issued the Order, is interviewed in this video tape by Elisabeth Healey, President of TASH's Executive Board.

- ***Informative and inspiring***
- ***Excellent education/training tool***
- ***A must-see for advocates, families, students and people entering the field***

TO ORDER: Send a check for $29.95 plus $4.00 postage and handling made payable to TASH. Specify your request for the Pennhurst tape. Mail your check and request to TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204. For more information, call Nancy Weiss, 410-828-8274, ext. 101 or e-mail: nweiss@tash.org.

NOT DEAD YET

BY VICKIE LOUDEN

We gratefully acknowledge the assistance of SAFE-Washington State and The Arc - King County for granting permission to republish the following article, which originally appeared in the Winter 1999 SAFE newsletter, What's Happening.

It is difficult to adequately describe the impact and benefits of the 1998 annual TASH conference, which took place in Seattle last December. One may note the hundreds of different sessions and presenters, catalogue the vast resources available, summarize the inspiring keynote presentations, list the numerous opportunities for further exploration and networking and still not come close to honoring the actual experiences available at the TASH gathering. In all fairness, one could also perhaps choose to list elements they disliked, sessions that disappointed them, or expectations left unfulfilled. Like life in general, the rich and vast landscape of TASH affords a full spectrum of experiences and perspectives and becomes what you make of it.

For me, the new insights into issues like classroom dynamics, paraprofessional possibilities and systems change were undeniably helpful. It was beneficial to hear of the experiences and lessons learned by other individuals around the country struggling with questions similar to my own, and it was inspiring and renewing to be challenged by many of the keynote individuals to expand possibilities, take risks and rise to the challenge inherent in the struggles of persons with disabilities.

One session in particular, however, lay far beyond all of these more obvious benefits, raised far more troubling questions, and ultimately struck the deepest chords within me. For me, it became the bottom line of the conference and the focus point of what all the rest is really about. Entitled "The Dark Side of Benevolence," this session by Norman Kunc and Emma Van der Klift challenged the very core of modern assumptions about individuals with disabilities by exploring current day questions concerning legalized euthanasia. It was a difficult session to experience and impossible to do justice to in a short article. Acknowledging that from the start, I nonetheless offer a few pieces from it, as the challenges it raised are too fundamental to ignore.

One of the primary points put forth is that something as extreme as euthanasia does not exist in a vacuum. Rather, it emerges from a long set of values and principles, which gradually and almost imperceptibly justify what might at first glimpse seem impossible. One such principle is that of "help." At first glance, "help" is almost universally considered a good thing. Upon closer scrutiny, "help" is revealed to have a broad range of implications, particularly help that is unsolicited. "Attacks of help" as Norman called them. How often does "help" help the helper more that the helpee? How often is it used to exert control rather than to offer respectful assistance? Likewise, "empathy" (putting oneself in another's shoes) is universally considered a strength and a positive skill. The presenters, however, cautioned against the limits of empathy. A person who does not currently have a disability might imagine they would rather die than experience a profound disability, and they project such feelings onto people they see. In reality, they can not know the full impact of such an experience. As an individual with significant disabilities, Norman offered profound testimony as to his assessment of the work of his own life.

It can be thought provoking to simply consider some of the following quotes that were shared:

"I believe that future doctors will be able to lay down a sound scientific basis for the theory of euthanasia, that the theologian will help by incorporating it in his statements and finally that the jurist, as representing the authority of the State over the doctor, will again enable him to render assistance to mankind, including even such unfortunate creatures...."
Karl Brandt,
Hitler's Personal Physician, Developer of Aktion T-4, The Nazi program for killing people with disabilities, at Nuremburg, 1949

"Thousands of ethicists and bioethicists, as they are called, professionally guide the unthinkable on its passage through the debatable on its way to becoming the justifiable until it is finally established as the unexceptional."
Richard John Neuhaus

"The voluntary self-elimination of individual and mortally diseased or crippled lives can only enhance public health and welfare."
Jack Kevorkian, 1990

Perhaps these issues may seem far-fetched, melodramatic, and sensational, certainly beyond the scope of our work with schools and classrooms and the kids we know. Each of us will decide for ourselves. It can be helpful, however, to really understand the nature of absolute exclusion in order to better illumine the struggle for inclusion. In the process, such a struggle emerges as a far more profound journey than a simple fight for more services. Who decides which life is valuable, which gifts have worth, and which are expendable? These issues are currently on trial and have yet to be decided. What kind of society will be a part of growing? Both exclusion and inclusion have their costs. Which price will we pay?

For more information, please contact Not Dead Yet at (708) 209-1500 or visit them on the web at www.notdeadyet.org.

Vickie Louden is a parent in the Lake Washington School District and one of the coordinators of SAFE in Washington.

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Women and Care

BY PERRI HARRIS

The Center on Human Policy has updated its information package on women with disabilities. In addition to sections concerning general issues, life histories and personal experiences, employment and rehabilitation, motherhood and reproductive rights, sexuality, sexual abuse, and fiction, the updated packet offers a new section covering the topic of women and care. What we offer here is a brief introduction to the topic of women and care, and to present several annotations of books, chapters, and articles which address emerging issues in the field.

This new section was added given the recent attention in disability studies to the concept of "women's work." Although there are exceptions, in many instances women do the majority of the day-to-day care of people with disabilities, including personal care, community care and inclusion, work in human service fields, and in friendships; yet for the most part, their efforts go unnoticed.

Far too often, the work that women do is understood as natural, or as an inherent part of being a woman. However, this research demonstrates that women as caregivers is not a role that comes naturally for women, it is negotiated and maintained by social interactions. This social construction of women as caregivers continues throughout their lives, and has powerful consequences on the way that their work is understood.

Also included in this section are discussions by women with disabilities who argue that the person being cared for is often left out of discussions of caring and caring relationships, and that this subject needs immediate attention. These writers assert that the discussion in this area should be located around equitable relationships between the women who care and the women who are being cared for.

FEMINIST PERSPECTIVES OF FAMILY CARE: POLICIES FOR GENDER JUSTICE

AUTHOR: Hooyman, N.R. & Gonyea, J.
PUBLICATION INFORMATION: 1995

Sage Publications, P.O. Box 5084, Newbury Park, CA 91359

Hooyman and Gonyea critically examine the act of caregiving through a feminist perspective. Given that over 75% of care provided to family members is provided by women, the authors analyze the impact of this caring on women's economic, social, and personal experiences. Furthermore, they examine how changing economic structures, changing families, and the changing workforce have affected the lives of women who provide care. The authors argue for structural changes in the economy, social institutions, and attitudes in order to improve the lives of women. Hooyman and Gonyea also explore the implications for social policy if caregiving is defined as a women's role and how current social policies are oppressive to women. Their recommendations for change include workplace supports, health care, long term care policies, and economic and social supports for caregivers.

CAREGIVERS AND DIFFERENCE

AUTHOR: Hillyer, B.
PUBLICATION INFORMATION: 1993

In B. Hillyer, Feminism and Disability (pp. 176-192). Norman, OK: University of Oklahoma Press.

University of Oklahoma Press, 1005 Asp Avenue, Norman, OK 73019-0445

This chapter of Feminism and Disability focuses on three main issues around caregiving. Hillyer explores the relationship of caregiving to women's role conditioning, to class barriers between caregivers, and to using caregiving networks to further explore feminist discussion of difference. She discusses how women have been conditioned to be caregivers and encouraged to be self sacrificing, and that feminist discourse needs to challenge these assumptions.

She further asserts that class and status play a role in women's caregiving. She argues that numerous caregivers are in financially difficult situations (either because they have given up their jobs to become caregivers or because they are paid caregivers in the low income range) and that these paid caregivers are often from ethnic minorities. These factors are usually different from the women they care for and, therefore, ethnic minorities or women from lower income situations are not seen as valued in a caregiving situation. They are not in positions of privilege and, therefore, are silenced in the discussions around caring and what is best for the person being cared for. In addition, these women are silenced in the sense that their stories and experiences do not easily cross class and status boundaries, thereby making it difficult for the carer and the person being cared for to understand each other.

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To help deal with this dilemma, Hillyer argues that caregiving networks can be used to explore the feminist discussion of difference. She feels that it is crucial to be able to listen to other women caregivers' stories and to value these experiences. This in turn could lead to consciousness raising groups and political action.

WHO CARES WINS? WOMEN, CARING, AND DISABILITY

AUTHOR: Keith, L.
PUBLICATION INFORMATION: 1992

Disability, Handicap & Society, 7(2), 167-176.

Keith's article provides an argument for research which does not alienate people with disabilities, while researching who cares for them. Too often, she asserts, feminist research on carers excludes the rights, power, and independence of people with disabilities and only depicts them as passive, helpless, and demanding. The author calls for the reconceptualization of research around the issue of care to make sure that all voices are represented, not only the voice of the person giving care. She offers as part of the solution the concept of citizenship and its affiliation with basic universal human rights as a way to fill this gap in research and in understanding the caring relationship.

FEMINIST RESEARCH AND 'COMMUNITY CARE'

AUTHOR: Morris, J.
PUBLICATION INFORMATION: 1991

In J. Morris, Pride against prejudice: Transforming attitudes to disability (pp. 146-168). Pittsburgh: New Society Publishers.

New Society Publishers, 4527 Springfield Avenue, Philadelphia, PA 19143

In this chapter, Morris argues that while feminists have paid much attention to 'community care' policies, they have virtually ignored the experiences of women with disabilities. She asserts that feminist concerns about women's roles as caregivers must be re-examined from a disability perspective. Traditionally, feminists have rejected community care policies which depend on women's unpaid labor in the home, thereby excluding women from the labor market and reinforcing their economic dependence on men. While these feminists would call for community care in residential settings, Morris argues that people with disabilities want services within the community, and therefore reject the traditional feminist view of community care.

The author claims that the differences between these two views is because the feminists who are writing and researching in the area of women and care do not actually need physical care themselves. In ignoring the experiences of those women who need care, they silence women with disabilities and force them into the role of the other. These feminists only see women as carers, not as those being cared for, thereby legitimizing one side and marginalizing the other.

In response to these feminists, Morris offers a critique from the perspective of a feminist with disabilities. She argues that research needs to examine the meaning of 'caring for' and 'caring about,' and especially the meaning of home (separated from the political feminist critique of the family). She asserts the feminist scholarship needs to understand this issue from a disability perspective and to see as the goal women with disabilities living in the community and receiving supports from caregivers whose work is valued, appreciated, and adequately compensated.

INDEPENDENT LIVES? COMMUNITY CARE AND DISABLED PEOPLE

AUTHOR: Morris, J.
PUBLICATION INFORMATION: 1993

Macmillan Press Ltd., Houndmills, Basingstoke, Hampshire RG21 2XS UNITED KINGDOM

This book is a qualitative study which explores the experiences of people with disabilities who receive help with daily living activities. Based on in-depth interviews with 50 people and using a feminist perspective and a disability rights perspective, Morris challenges the discourse around community care policies. She illustrates how residential care is often replaced by institutionalization in community settings, and further challenges policy makers and those who provide care to recognize the basic civil rights of people with disabilities, and that part of their civil rights is to receive physical help.

"BUT THEY NEED ME!" THE STORY OF ANNA LONDON

AUTHOR: Shoultz, B.
PUBLICATION INFORMATION: 1995

In S. J. Taylor, R. Bogdan, & Z. M. Lutfiyya (Eds.), The variety of community experience: Qualitative studies of family and community life (pp. 9-22). Baltimore: Paul H. Brookes Publishing Co.

Paul H. Brookes Publishing Co., P.O. Box 19624, Baltimore, MD 21285-0624

This chapter tells the story of Anna London, a women with a developmental disability who gives extensive help and care to others, especially her family members. This is a unique account, because most of the literature on caring centers around people without disabilities caring for people with disabilities, yet this story features a woman with a disability who devotes much of her life

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to caring for others. Anna, who has several disabilities (developmental and psychiatric to name a few), is not dependent in any way. In fact, she lives independently and has held her family together because of the work she does for them. She babysits for her brother's three children and her sister's children so that they can hold down jobs, she helps her mother with her personal care and housework, and she arranges her schedule around the needs of her family members. She also helps her friends, whether it be to give them some money, a place to stay, helping them with a move, or accompanying them to the doctor. Anna sees her role in life as one of helping others, and she takes this role seriously. She enjoys caring for others, but it sometimes leaves her feeling stressed or sad. This is especially obvious when Anna needs care, and only her mother can be counted on to help.

The author highlights Anna's personal history as well as her current situation. She also explores Anna's other roles in addition to caregiving. Not only is she a daughter, a sister, and a "carer," she also is a community member, a church goer, and has a number of client roles, such as medical patient and mental health system participant. Shoultz also examines Anna's socio-economic status, her class and religion, the human service system and its impact on Anna's life, and the meaning of being connected.

A MOTHER'S WORK IS NEVER DONE: CONSTRUCTING A "NORMAL" FAMILY LIFE.

AUTHOR: Traustadottir, R.
PUBLICATION INFORMATION: 1995

In S. J. Taylor, R. Bogdan, & Z. M. Lutfiyya (Eds.), The variety of community experience: Qualitative studies of family and community life (pp. 47-65). Baltimore: Paul H. Brookes Publishing Co.

Paul H. Brookes Publishing Co., P.O. Box 19624, Baltimore, MD 21285-0624

The author examines the everyday lives of families of children with disabilities. She explores the ways in which the family attempts to construct an "ordinary" or "normal" family life. Traustadottir analyzes the gendered organization involved in constructing and maintaining a normal family life. Through qualitative research based on interviews and participant observation, Traustadottir found that families of children with disabilities devote much time trying to lead a "normal" family life. For the most part this meant following the traditional family pattern of full time wife and mother and working father. She suggests that presence of disability in the family causes parents to compensate by conforming as closely as possible to traditional gender roles.

The author also discusses implications for professionals, stating that they need to be aware of individual perspectives of families. She also addresses how broader socio-cultural issues such as class, race, ethnicity, and gender influence the lives of families of children with disabilities.

THE MEANING OF CARE IN THE LIVES OF MOTHERS OF CHILDREN WITH DISABILITIES

AUTHOR: Traustadottir, R.
PUBLICATION INFORMATION: 1991

In S. J. Taylor, R. Bogdan, & J. A. Racino (Eds.), Life in the community: Case studies of organizations supporting people with disabilities (pp.185-194). Baltimore: Paul H. Brookes Publishing Co.

Paul H. Brookes Publishing Co., P.O. Box 19624, Baltimore, MD 21285-0624

In this qualitative chapter, Traustadottir explores the gender differences in caring for a child with a disability within the family. She discovered that the responsibility for caring is based on gender. The study revealed the term "caring" as a complex phenomenon that has at least three meanings. Caring for: the work, means acquiring specialized knowledge and techniques which are associated with professional work (not traditional mothering work). The second definition is caring about: the love. This refers to relationships and emotions. The third definition is the extended caring role. The meaning of care extends from a woman's own child to broader community or societal concerns surrounding people with disabilities and the way they are treated in society.

The author also discusses gender roles and the responsibility of caring. The women are usually responsible. This begins when she decides to keep her child at home rather than in a residential setting. In many instances, this tends to be the mother's decision because it is understood that she will be the primary care giver. In addition to this work, she is responsible for the housework and other family work. Furthermore, the baby is not seen as a restriction on family life if it only restricts the mother. However, if the family feels restricted, then the situation is considered problematic. Some women see the job of caring as their "natural" responsibility, while others resist this traditional gender role.

The author concludes by stating that disability studies need to look at gender as a critical issue and need to examine issues of gender and the roles of mothers and fathers in families.

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CONTRADICTIONS IN CARING

AUTHOR: Walmsley, J.
PUBLICATION INFORMATION: 1993

Disability, Handicap & Society, 8(2), 129-141.

Walmsley uses research about the experiences of women with learning difficulties and shows how they, like womenwithout disabilities, often find themselves in caring roles and they, too, find this role both sustaining and frustrating. She argues that to attempt to divide the experiences of the "carer" and the "dependent" is virtually impossible because the relationships are both reciprocal and interdependent. The author argues for a new understanding of the caring relationship in that the carer and the cared for be considered together, not in opposition to one another.

THE CARING WIFE: THE EXPERIENCE OF CARING FOR A SEVERELY DISABLED HUSBAND IN THE COMMUNITY

AUTHOR: Whalley Hammell, K.R.
PUBLICATION INFORMATION: 1992

Disability, Handicap & Society, 7(4), 349-362.

This article explores the experiences of wives who assume a caring role following the onset of a husband's significant disability. Given the fact that modern medicine has increased the chances of survival of a major injury, people with disabilities are returning to their communities and may need care. The author examines the social expectations of women's role in the provision of care for people with significant disabilities. The author argues that community care actually means care by women, and she looks at who cares for people with disabilities in the community, why these women care, the impact of caring on these women, how to support carers (what their needs are), and some implications of community care policies.

CAREERS IN CARING: MOTHERS OF CHILDREN WITH DISABILITIES

AUTHOR: Wickham-Searl, P.
PUBLICATION INFORMATION: 1992

Disability, Handicap & Society, 7(1), 5-18.

The author studied the experiences of 14 women who were mothers of children with disabilities. These women had extended their family caregiving roles to public work in the disability field in order to help other families. Their work often stemmed from a lack of available services and programs for their own children, and their insights here led them to help other parents. Several themes developed during these interviews. Among them are the reliance on personal experience for guidance in the caregiving and public work process, the importance of their mothering role and their children, the realization that people with disabilities and their caregivers are not valued in society, and the search for legitimization for their work.

The preparation of this article was supported in part by the National Resource Center on Community Integration, Center on Human Policy, School of Education, Syracuse University, through the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133D50037. No endorsement by the U.S. Department of Education should be inferred. The Center on Human Policy subcontracts with TASH for space in this Newsletter.

To receive information on Women with Disabilities: Issues, Resources, Connections, Revised and Updated, write to:

Center on Human Policy
ATTN: Rachael Zubal
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280

News from Virginia Commonwealth University

Virginia Commonwealth University, announces a new employment-oriented web site for persons with disabilities. The site is linked from GLADNET's page "Research Institutes, Universities, Rehabilitation Centers."

On April 2, 1999, The Virginia Commonwealth University Rehabilitation Research and Training Center on Workplace Supports publicly introduced its new niche portal, "Your Gateway to Employment for People with Disabilities," http://www.worksupport.com/

A portal is a souped-up WEB site designed as a hub where users can gather information, locate Internet resources and branch into related sites. The site features information across the following 7 broad categories, as well as perspectives from leaders in employment and disability, innovative employers & outstanding workers: Accommodations; Bridge to Employment; Disability Management; Law and Policy; Supported Employment; Workforce Diversity; and Workforce Training.

Canada's Latimer Case: Implications for Equal Justice

BY DICK SOBSEY

On Sunday, October 24, 1993, a twelve-year-old girl named Tracy Latimer was murdered in the front seat of a pick-up truck on a Saskatchewan farm. Less than two weeks later, her father confessed the killing to the police. With few facts in dispute, one might expect an open-and-shut case, but that is not what happened.

Five years later, Robert Latimer has been convicted twice of murdering his daughter, but has served only a few days in jail. He is free on his 1200 acre farm awaiting a third trial in a case that has already been to the Supreme Court once and is expected to find its way back there again. The issues discussed at trial led to a sharp division between disability rights advocates and other Canadians. Most people with disabilities and their advocates believe that the penalty for killing a child with severe cerebral palsy must be equal to the penalty for killing any other child. The majority of other Canadians see Robert Latimer as a hero who saved his daughter from a life of misery. They believe that even the legally mandated minimum sentence is too severe.

The life and death of Tracy Latimer

Tracy Latimer had significant disabilities. She could not see much, had severe cerebral palsy, and appeared to have a significant cognitive disability, although it is difficult to measure cognitive skills accurately in someone with significant physical and sensory impairment. When she died, she was just a month away from her 13th birthday.

She attended a special program for children with developmental disabilities at the school that her brother and sister attended. She seemed to enjoy many school activities, especially music, "pet therapy," and using the swimming pool. She also enjoyed family activities. People said that she liked the excited voices of the announcers when hockey games were on television and loved bonfires on the family farm. These things made her laugh and smile. Tracy's life, however, was not all smiles and laughter. Like thousands of children with severe cerebral palsy Tracy had some serious challenges. She had a lot of difficulty eating. Her severe scoliosis had required surgery in 1992. A dislocated hip was causing her pain at times and her doctor recommended another operation to fix it.

She spent the summer of 1993 in a group home while her mother was in the later stages of a pregnancy, and there had been some discussion of longer-term placement. Nevertheless, Tracy returned home in October of 1993 after the new baby, Lee, was born. Fall was a busy time for the family, with a new baby and harvest season on the farm.

The people at her school said she had some discomfort, but indicated that Tracy was happy most of the time. Her mother kept a journal that frequently used words like "cheerful" to describe how Tracy was acting.

On Sunday, October 24, 1993, Tracy had been back home for only three weeks. At about 11 a.m., her mother took her brothers and sister to church and Tracy stayed home with her father. When they were alone on the farm, Robert Latimer carried his daughter out of the house and propped her in a sitting position in his pickup truck. He quickly set-up the pipes and hoses he had prepared in advance and started the engine, flooding the cab of the truck with deadly carbon monoxide. Then, according to police, he watched his daughter die before returning her body to bed and hiding the evidence.

After Mrs. Latimer returned at about 1 p.m., she looked in on her daughter and found her dead. Mr. Latimer suggested that she must have died in her sleep. Police became suspicious because of his excessive nervousness and his determination to have his daughter's body cremated as soon as possible in spite of his wife's apparent surprise at the suggestion.

Lab tests revealed that Tracy Latimer had been killed with carbon monoxide gas. Although Mr. Latimer initially denied any involvement, the evidence against him was strong. He was the only person with opportunity.

It was the police who first raised the issue of "mercy killing" in an effort to get Robert Latimer to confess. One officer asked, "Is this something you did out of love for your daughter?" Another stated: "I'm sure this is something that you had not planned to do or something that you had not intended to do and certainly something you did want to do, but it's something — because you're a loving type of individual — you felt you had to do for your daughter. Is that right?"

Advocates for people with disabilities are appalled by the assumption that killing a child who had cerebral palsy would be considered any more compassionate than killing any other child. They are shocked that a clear majority of the media and the Canadian public would assume that Tracy Latimer's life could not have been worth living and that the father who chose to snuff it out should be viewed as a hero rather than a murderer.

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Canada's Latimer Case: Implications for Equal Justice

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Robert Latimer listened to these questions in silence, but when asked again "Is that right?" he began to weep and said, "My priority was to put her out of her pain." Shortly thereafter, he described the details of how the killing had taken place. Although Mr. Latimer later tried to retract his confession and never took the stand to deny or defend his actions in court, he also gave a videotaped interview to a reporter that did not deny what he had done but suggesting that his actions were not criminal.

Mercy killing on trial

In the videotaped interview played at his trial, Robert Latimer said, "I honestly don't believe that there was ever any crime committed here." Mr. Latimer's legal representatives argued that Robert Latimer acted in his daughter's best interest. They argue not only that we should consider his intentions, but also that we should assume that his intentions were compassionate, even though he remained silent in court.

Advocates for people with disabilities are appalled by the assumption that killing a child who had cerebral palsy would be considered any more compassionate than killing any other child. They are shocked that a clear majority of the media and the Canadian public would assume that Tracy Latimer's life could not have been worth living and that the father who chose to snuff it out should be viewed as a hero rather than a murderer. A poll conducted by a newspaper during the first trial indicated that 95% of readers supported Robert Latimer's killing of his daughter. While support has declined, a January 1999 Angus Reid poll found that 73% of Canadians still believed he acted from compassion and should be treated with greater leniency.

> **"The real motivation for mercy killing has little to do with the offender's feelings of compassion and pity for the victim. The sense of power and control the offender derives from killing is usually the real motive."**
> **(Douglas, Burgess, Burgess & Ressler, 1992)**

Equally disturbing was the fact that a Canadian Senate Committee filed a report after the trial recommending that a new class of homicide be legally defined in Canada called compassionate homicide with no minimum sentence. Effectively such a law would create a lesser class of murder for those who kill people with illnesses or disabilities. Every scenario discussed as possible compassionate homicides involves victims who had illnesses or disabilities. No one suggests compassionate homicide because the victim is poor, abused, an object of discrimination, or just plain unhappy.

Around the time that Susan Smith confessed to killing her two children in South Carolina, saying she could not stand seeing them suffer through their parents' divorce, no one suggested that her compassion merited a lighter sentence. Since intentions can not be directly observed and the burden of proof must be on the prosecution, it would be effectively become the responsibility of the prosecution to prove that the killer of a person with an illness or disability could not have been feeling compassion. This would be virtually impossible to prove, especially since the accused has a right to remain silent to prevent self-incrimination.

The most disturbing aspect of the case by far, however, came after Robert Latimer's second trial. A February 1997 appeal of his first conviction to the Supreme Court of Canada had ordered a new trial and he had been convicted again of second degree murder by a jury. Under Canadian law, the minimum penalty was life in prison without possibility of parole for ten years. On December 1, 1997 the judge who tried the case, Judge Ted Noble, granted a constitutional exemption that would have sentenced Robert Latimer to one year in prison plus one year house arrest on his farm. This extraordinary exemption claimed that Mr. Latimer's sentence, the lightest allowed by law, was cruel and unusual in this case. The judge's opinion actually listed a number of other homicides against people with illnesses and disabilities, pointing out that those who killed them typically got off with lighter sentences through plea bargains or prosecutorial decisions to bring lesser charges. Therefore, he argued that Mr. Latimer should also be given a light sentence. Both sides appealed. Mr. Latimer's lawyers argued that even one year in jail was too much; the prosecution argued that Mr. Latimer must serve the minimum 10 years.

In November 1998, the Saskatchewan Court of Appeals upheld Robert Latimer's original sentence of ten years without chance of parole. Mr. Latimer has again appealed and remains on his farm awaiting trial.

Equal Protection of the Law

Tracy Latimer was not the first or last person with a developmental disability to be murdered. Researchers at the University of Alberta currently maintain data on about 740 cases, many with multiple victims. (See More Victims of Homicide sidebar on page 32). Most cases get little attention, and often those who perpetrate these crimes receive sympathy rather than punishment. What brought this case to prominence?

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One important factor was a deliberate attempt by Mr. Latimer's lawyers to create public sympathy and to try the case in the media as well as the courtroom. While Mr. Latimer has lost so far in the courtroom, he has won widespread support from the public and media. In fact, shortly after his arrest, Mr. Latimer's lawyer indicated that building public sympathy for his client would be a critical strategy in the case.

Another factor in the widespread attention this case received was the nature of the defense. In many other cases involving the killing of children with disabilities by parents, the defense argues that the parent was overwhelmed by stress and made a bad decision. This allows judges and juries to acquit without endorsing child murder. Robert Latimer's defense was that he was rational and made a good decision. Acquittal requires endorsing his actions and implicitly endorsing the murder of other children with disabilities. Whether it was Mr. Latimer's decision or his lawyers' to use the rational-decision defense is unclear. It is much less likely to result in acquittal, but it does ensure media and public interest.

The decision to try this case on the merits of mercy killing also led to another factor that built public interest. Advocates for disability rights organizations and advocates for the "right to die" movement were drawn into the case. The executive director of one dying-with-dignity group suggested that living with Tracy for 12 years was already enough of a sentence for Mr. Latimer. Statements like this clearly drew disability rights groups into the fray. The Council of Canadians with Disabilities, the Saskatchewan Voice of Persons with Disabilities, People First Canada, and the Canadian Association for Community Living became actively involved and were granted intervenor status for some appeals. This status recognized their legitimate interest in the matters before the courts and allowed input on some issues.

Some child abuse prevention organizations and human rights organizations supported the efforts of disability rights organizations in asking for equal protection under the law. Robert Latimer is now awaiting further appeal. The issues are straightforward. If he wins, parents have a right to kill children with disabilities if they claim that they do it because they believe it is right. If Mr. Latimer loses his appeal, Canada will have moved one step closer to equal protection under the law for people with developmental disabilities.

While the Latimer case highlights these issues, they are not unique to Canada. There is widespread and growing public support for so-called "mercy killers" based on the myth that these are compassionate acts. Those who have closely studied "mercy killings" disagree. According to the Crime Classification Manual that was developed as a result of a ten year study by the FBI's leading criminal profilers and some of America's leading criminologists:

The real motivation for mercy killing has little to do with the offender's feelings of compassion and pity for the victim. The sense of power and control the offender derives from killing is usually the real motive (Douglas, Burgess, Burgess, & Ressler, 1992).

◆ ◆ ◆ ◆

Sources

Council of Canadians with Disabilities. (1998). The Latimer Case: The reflections of people with disabilities. Winnipeg: Author.

Douglas, J.E., Burgess, A.W., Burgess, A.G., & Ressler, R.K. (1992). Crime Classification Manual. San Francisco: Jossey-Bass.

Her Majesty the Queen and Robert W. Latimer. Court of Queen's Bench for Saskatchewan, Judicial Centre of Battleford.

SIDEBAR

More Victims of Homicide

Tracy Latimer is only one of many people with developmental disabilities who die as a result of homicide, neglect, or abuse. The following provides a few examples of other cases.

◆Casey Albury was a young woman with autism. Her mother strangled her after trying unsuccessfully to persuade her to jump off a bridge in 1997. Her mother was originally sentenced to four years, but the sentence was reduced to 18 months by a New Zealand judge saying that since the case was exceptional, there was no need for a deterrent sentence.

◆Joseph "Jojo" Bacaylan, a 29-year-old resident of Agnews Developmental Center who had significant and multiple disabilities, including mental retardation, died of multiple stab wounds and a beating by an institutional staff member. According to California medical authorities, institutional physicians failed to treat his wounds and filed a false report listing his cause of death as "cardiopulmonary arrest of unknown cause."

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Canada's Latimer Case: Implications for Equal Justice

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◆Katy Lynn Baker was a 10-year-old girl with Rett syndrome in British Columbia. She starved to death in 1996. Her death was ruled a homicide but no charges have ever been filed.

◆Robert Ballard was a 33-year-old man with a mental disability who lived in the small town of Salina, Oklahoma. Two teenagers broke into his house in 1994 and beat him to death with the electronic communication device that he used.

◆Charles Antoine Blais was a six-year-old boy with autism when his mother drowned him in their bathtub in Montreal. She was allowed to plead guilty to manslaughter and given a 23 month suspended sentence.

◆Kay Lynn Kuffer, had multiple disabilities. She was 15 years old and weighed 15 pounds when she died of starvation and dehydration in Janesville, Wisconsin, in November 1998. She did not attend school and social services had lost contact with her family. She had not been to the doctor in 6 years. Her mother was charged with neglect but found incompetent to stand trial.

◆Ronald Lambert was only 11 years old when an aide at the St. Amant Centre in Manitoba smothered him in 1977. The aide confessed in 1995 and was sentenced to two years in prison. Ironically, he claimed that he had already confessed to the institutional administration shortly after committing the crime but they chose to ignore it.

◆Louis "Buddy" Musso was a 59-year-old man with a developmental disability in Texas. In 1998, five people were charged with beating him to death over several days as a punishment for breaking a Christmas ornament.

◆Lenka Orilikova had multiple disabilities. She was 14 when her father — who was fighting with her mother — turned his rage on Lenka, stabbing her to death in 1998 at their home in Madison, Wisconsin.

◆Matthew Brent Richmond was 12 and had a developmental disability. On New Year's Day 1997, he soiled himself. To punish him, his mother's boyfriend held him in a tub of scalding water. He died of extensive burns. The case led to tougher laws for killing a child in Ohio.

◆Amy Robinson was riding her bicycle to the grocery store where she bagged groceries when two men she knew slightly offered her a ride in a pick-up truck on February 15, 1998 in Arlington, Texas. They did not want sex or money from Amy; they simply tortured and killed her. According to their videotaped confession, they "busted out laughing" when she died. One perpetrator was sentenced to death. A second young man is awaiting trial.

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Justin Dart Responds To Princeton on Singer's "Ethics"

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or for more information contact:

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Chair, Justice For All
jfa@mailbot.com
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1999 Calendar of TASH Chapter and Member-Sponsored Conferences

JUNE

Where the Rubber Meets the Road TASH-NE Conference
June 11-12
Lake Morey Inn, Fairlee, Vermont
Contacts: VT/Susan Yuan,
E-mail: syuan@zoo.uvm.edu
NH/Mike Shields,
E-mail: mshields@rowing.mv.com

Eleven State Northeast Atlantic Conference on Self-Determination
June 25-26
Valley Forge Sheraton, Valley Forge, PA
Contact: Speaking for Ourselves
Phone: 800-867-3330
E-mail: speakingfo@aol.com

JULY

1999 Toronto Summer Institute
July 3-9
Toronto, Canada
Contact: Inclusion Press
Phone: 416-658-5363
E-mail: 74640.112@compuserve.com

Project CHOICES Summer Institute: "Kids: Our Future"
July 22 and 22
Crowne Plaza Hotel, Springfield, Illinois
Contact: Project CHOICES
Phone: 630-778-4508
E-mail: ECHOICES@aol.com

CAL-TASH Summer Symposiums in Santa Barbara
July 26-27 - "School Inclusion"
July 29-30 - "Positive Behavior Support"
Contact: Eileen Medina
Phone: 805-967-2042
E-mail: cal-tash@ceo.sbceo.k12.ca.us

SEPTEMBER

National Spinal Cord Injury Association
Annual Meeting and Education Conference
September 26-29
Washington, D.C. Marriott - Metro Center
Contact: Denise Marshall
Phone: 410-828-8274, ext. 103
E-mail: dmarsh@tash.org

OCTOBER

8th Annual St. Amant Centre Conference "20th Century Trends, 21st Century Services?"
October 7 and 8
CanadInn, Winnipeg, Manitoba
Contact: Colette Choquette
Phone: 204-256-4301, ext. 298

DECEMBER

Annual TASH International Conference
"TASH 2000 - Our Turn Now"
December 8-11
Chicago Hilton and Towers
Contact: Kelly Nelson
Phone: 410-828-8274, ext. 105 or 1-800-482-8274, ext. 105
E-mail: knelson@tash.org

Do you have an upcoming TASH chapter meeting or member-sponsored conference that you would like to announce in the Newsletter? Send notice of the conference to Denise Marshall at dmarsh@tash.org at least 6 weeks before the event date. We will make every effort to include the event in the meetings calendar.

Institute on Abuse & Neglect of Persons with Disabilities

" Most people with disabilities will experience significant abuse, violence, or neglect sometime in their lives and people with disabilities are more than twice as likely to experience crimes of violence as people without disabilities."

- Dick Sobsey

This Institute is designed to bring together internationally known experts in the field of abuse, neglect, and victimization of individuals with developmental disabilities with researchers, practitioners, policymakers, and consumers to discuss the latest in research and best practices. For three days, on the beautiful New Hampshire seacoast, learn about important information related to the victimization of individuals with disabilities, and policy and practice, initiatives to create safe and secure communities for all.

Featured Speakers:

Dick Sobsey, Ph.D ▪ David Finkelhor, Ph.D ▪ Patricia Sullivan, Ph.D ▪ Ruth Ryan, MD. ▪ Deb Jones ▪ John Knutson, Ph.D ▪ Tanis Doe, Ph.D

For registration information contact Deb at The Institute on Disability/UAP 603.228.2084 or visit us on the web at http://iod.unh.edu

Co-Sponsors: UNH Institute on Disability/UAP and the UNH Continuing Education • NH Division of Children Youth and Families • NH Division of Developmental Disabilities Services

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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General Membership (individual)	$88
Agency/business/university/college/library/school (allows 3 conference attendees at the member rate)	$200
Self Advocate, Parent, Full Time Student, Direct Careworker/Para professional/Personal Attendant (for whom payment of full fee would present a hardship)	$45
Family (group rate)	$136
Lifetime Member	$1000

Add $10 for postage costs for members in Canada and $25 for members outside the U.S. and Canada.

Funds must be submitted in U.S. dollars and checks must be drawn on a U.S. bank. Add a $20 processing fee if check is not drawn on a U.S. bank. If you would like to charge your membership, please fill in the necessary information.

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( ) Include an additional $15 if you are applying for an individual membership or $30 if you are applying for an organizational membership and also want to become a member of your local chapter.

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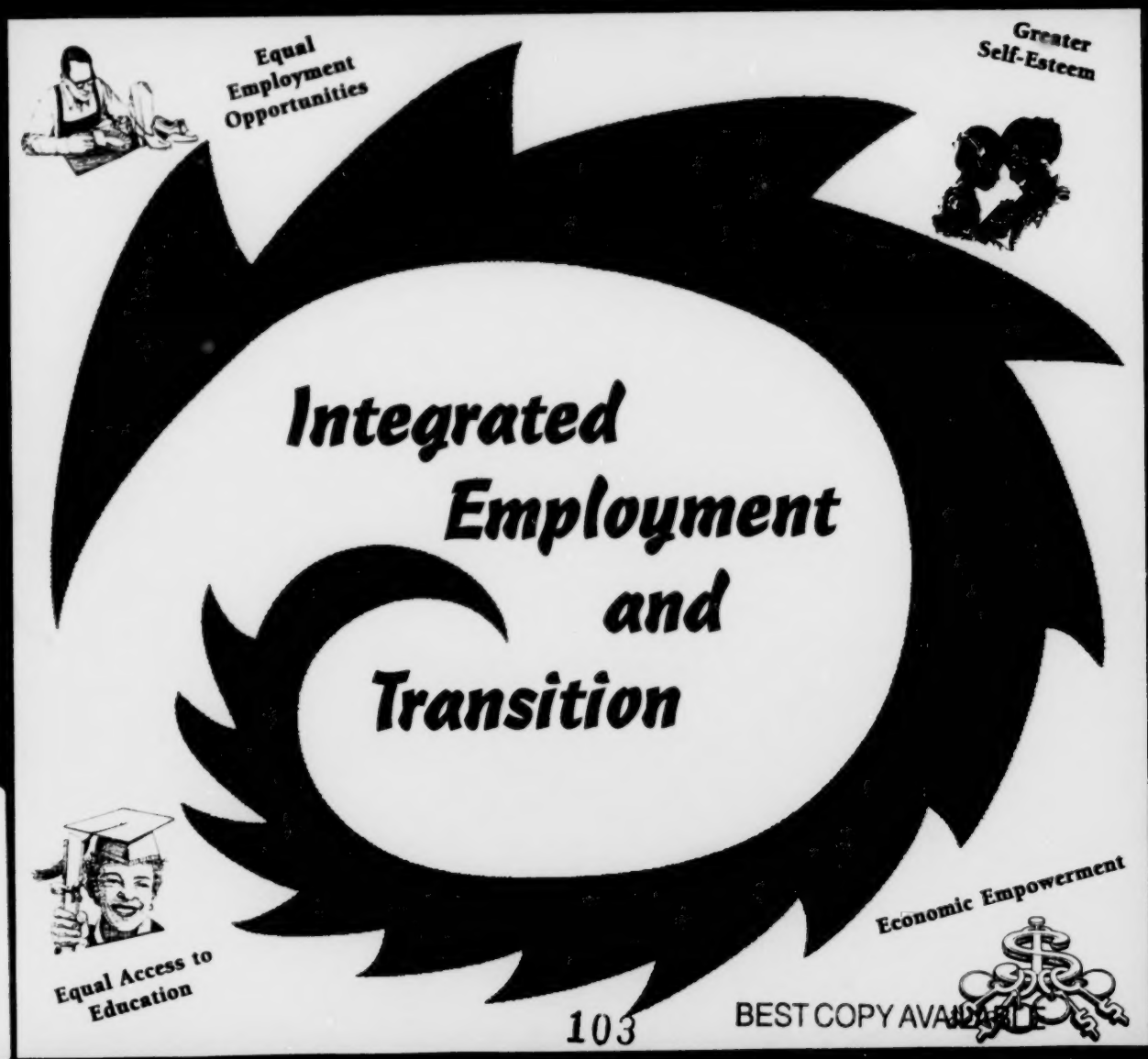

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

~

Building communities in which no one is segregated and everyone belongs;

~

Forging new alliances that embrace diversity;

~

Advocating for opportunities and rights;

~

Eradicating injustices and inequities;

~

Supporting research and disseminating knowledge and information;

~

Promoting inclusive education;

~

Supporting progressive legislation and litigation; and,

~

Promoting excellence in services.

From the Executive Director
BY NANCY WEISS

Who are our members and how can we best serve them?

Over the past few months we have learned a lot about who our members are, why people join TASH and the additional benefits, information, and supports they are seeking. We first analyzed our membership data. Here is what we learned:

- About 49% of our members are members of International TASH only; about 34% are members of both the international organization and their local chapter, and 17% are members of only their chapter.

- Approximately 52% of our members pay the regular, individual rate; about 24% pay the reduced rate; about 20% are agency/organizational members; approximately 2% have a family group membership and about 2% are lifetime members.

- The largest single group of members are parents/family members (585). Close behind are educators (571) and students (555). We have 200 university-level professors as members, 190 school administrators, and 181 staff development specialists. One hundred and fifty-five of our members are in the early childhood field and 149 of our members are advocates or friends. Public policy advocates comprise 131 of our members and 125 work in the adult services field.

Continued on page 3

Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about the 1999 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations, (410) 828-TASH, Ext. 100 or rholsey@tash.org
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- **For information on the Journal (JASH), call:** Linda Bambara, Editor-in-Chief, at (610) 758-3271, e-mail: LMB1@lehigh.edu
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Who are our members and how can we best serve them?

Continued from page 2

We have 104 social workers as members, 94 behavior specialists, 85 people who work in supported employment and 83 psychologists. Eighty-five TASH members are government employees, 71 are self-advocates and 69 members are case managers. We have 60 regular educators as members, 59 speech/language pathologists, 34 OTs or PTs, 31 personal assistants and 28 members are in a legal services field.

● About 92% of our members are from the U.S., with members from every state and from Puerto Rico, Guam and the Virgin Islands. Another 4% are from Canada. The remaining 4% of members are spread around the world, representing 33 other countries. The countries having the most international members are Australia (62) and Japan (38).

The second method we used to learn about our members was an analysis of our members' interests. New and renewing TASH members are asked to indicate the committees in which they would be interested in participating. Here are the results:

Number of TASH Members Expressing Interest in Various TASH Topics

Education	96
Positive Approaches	64
Community Living	58
Early Childhood	48
Family	41
Persons with Special Health Care Needs	40
Personnel Preparation	34
Integrated Employment and Careers	33
Governmental Affairs	31
Chapter Operating Committee	29
Leisure and Recreation	27
International Issues	23
Multicultural Issues	10
Paraeducator Issues	14
Related Services	13
Peace	12
Publications	9
Membership	8
Sexual Orientation	8
Media	6

Finally, in our quest to get to know our members better, we sent out a survey with every membership card for a year. We received 971 responses.

We asked members to specify which benefits inspired them to join TASH or renew their membership. The *Newsletter* got the most votes. JASH came in second. Other benefits, in the order in which they were selected were:

◆Current Information on Best Practices;

◆Legislative Updates;

◆The Annual Conference Discount;

◆Grassroots Advocacy Efforts;

◆Information and Referral;

◆Legislative Representation;

◆Discounts on TASH Materials and Merchandise; and,

◆Chapter Activities

When asked what additional member benefits they would like to see in the future, members suggested

◆ regional workshops and conferences;

◆ continuing to enhance the web site;

◆ making professional liability insurance available;

◆ more legislative updates;

◆ improving opportunities for member networking;

◆ a job network, a membership directory;

◆ providing information on grants that are available; and

◆ more chapter activities

When asked what topics members would like to see covered in future TASH publications, conferences and workshops members listed: self-determination; assistive technology; supported employment; community living issues; information on related services; home-ownership; facilitated communication; transition planning; early intervention; sibling issues; accessible transportation; international issues; recreation; alternative assessment; guardianship issues; peer advocacy training; action research; issues of aging; managed care; issues affecting people who are dually diagnosed; staff training; sexuality and sexual preference; behavior support; and augmentative communication.

Finally, when asked what current issues they would like to see the TASH membership addressing, the following concerns were named: changing TASH's name, MiCASSA, assisted suicide, family support issues, inclusion, criminal justice issues, inclusive recreational opportunities, IDEA implementation and enforcement, and waiting lists.

What are we going to do with all of the new information we've learned about our members? The first step is that all of this information will be reviewed by our Membership Committee and the Board. We will select a number of goals based on what we know about why people join TASH and the additional benefits, information, and supports they are seeking. Information on topics members would like to see covered in future TASH publications, conferences and workshops will be forwarded to the staff and committees working in these areas.

The membership committee welcomes new participants. If you have an interest in addressing the needs of members, contact Rose Holsey (410-828-8274, ext. 100 or rholsey@tash.org) for information on upcoming committee meetings.

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"TASH 2000: Our Turn Now"

Chicago Hilton and Towers ◆ December 8-11

Tentative Conference Agenda

Pre-Conference Activities

Wednesday, December 8, 1999

7:30 AM - 8:45 AM	TASH Tech Registration
9:30 AM - 4:30 PM	Club TASH Day Care/Youth Activities
9:00 AM - 4:00 PM	TASH Tech Workshops
9:00 AM - 4:00 PM	TASH Development and Leadership Training
2:00 PM - 8:00 PM	TASH Conference Registration
4:30 PM - 5:00 PM	Welcome to TASH
5:00 PM - 7:00 PM	Opening Reception in the TASH Exhibit Hall

Thursday, December 9, 1999

7:30 AM - 1:00 PM	TASH Conference Registration
7:30 AM - 9:00 AM	TASH Exhibit Hall Open
8:30 AM - 5:45 PM	Club TASH Day Care/Youth Activities
8:30 AM - 10:00 AM	General Session
10:15 AM - 5:30 PM	Conference Sessions and Poster Presentations
11:00 AM - 6:00 PM	TASH Exhibit Hall Open
5:30 PM - 7:00 PM	Reception

Friday, December 10, 1999

7:30 AM - 11:00 AM	TASH Conference Registration
7:30 AM - 10:30 AM	TASH Exhibit Hall Open
8:30 AM - 5:45 PM	Club TASH Day Care/Youth Activities
8:00 AM - 10:15 AM	Conference Sessions and Poster Presentations
10:30 AM - 12:00 PM	General Session
12:15 PM - 4:45 PM	Conference Sessions and Poster Presentations
1:00 PM - 7:00 PM	TASH Exhibit Hall Open
5:30 PM - 7:00 PM	Reception
6:30 PM - 8:00 PM	TASH Open Forum and Business Meeting

Saturday, December 11, 1999

7:30 AM - 9:00 AM	TASH Conference Registration
7:30 AM - 12:00 PM	TASH Exhibit Hall Open
8:30 AM - 1:00 PM	Club TASH Day Care/Youth Activities
8:00 AM - 12:45 PM	Conference Sessions

1999 TASH KEYNOTE SPEAKERS

THURSDAY, DECEMBER 9, 1999

Rich Villa

As the President of Bayridge Consortium, Rich provides training and consultation in areas such as collaborative teaming, creative solutions, systems change, and inclusion. He also gives technical assistance to school districts, departments of education, and advocacy groups across the country and around the globe.

Diane Coleman

Diane has served on the governing boards of national, state and local disability-related organizations and policy-related committees, has authored numerous articles on disability-related topics and spoken extensively on topics pertaining to disability rights and health care issues. Diane has worked as an organizer for ADAPT and is founder of Not Dead Yet, a national grassroots disability rights organization.

Kyle Glosier

Kyle is a middle-school student and self advocate who uses augmentative communication. Having spoken at conferences and rallies since he was a young child, Kyle is now an experienced national and international speaker. Kyle is also an active member of ADAPT.

Jeff Moyer

Jeff is an internationally known disability advocate, songwriter, performer, author and leader whose work on the cutting edge of the disability rights movement has spanned over 25 years. Jeff's work challenges, uplifts and unites communities through recognizing the essential contributions of individuals, families and all members of the teams that advocate, support and educate.

FRIDAY, DECEMBER 10, 1999

Anne Donnellan

Anne is a Professor in the School of Education at the University of Wisconsin, Madison. Her keynote address, titled "Absence of Evidence - Not Evidence of Absence," will discuss how 19th century social biases and 20th century testing continue to condemn people with mental retardation, autism, and other disabilities to second class citizenship. Ann will inspire us to lead special education, rehabilitation and human services into the next millennium with creative new approaches to understanding and serving people who have been labeled.

Rosangela Berman-Bieler

Founder of the Independent Living Movement in Brazil, Rosangela is also the founder and current president of the Inter-American Institute on Disability (IID). Through her work with IID, Rosangela works to promote cooperation for the development and empowerment of people with disabilities in the Inter-American region, as well as Spanish and Portuguese speaking countries of Europe and Africa. Rosangela has been a quadriplegic since an automobile accident in 1976, and uses a wheelchair. Her keynote address will focus on the concept of "inclusion" as a new paradigm for the millenium and on the importance of international cooperation regarding disability issues worldwide.

TASH Conference Registration

"TASH 2000: Our Turn Now"

Chicago Hilton and Towers
December 8–11, 1999

Mail form to: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore MD 21204 *or*
Fax form to: TASH, (410) 828-6706
Questions? Call: 1-800-482-TASH (8274)
Email: registration@tash.org
TDD (410) 828-1306
This form can also be found on our website www.tash.org

TASH Office Use Only
Org _____
Cust _____
Reg _____
Rec _____
Init _____

Agency / Organization / School Information: (if applicable)

Name of Agency/Org/School: _____
❑ This organization is a current TASH Member # _____
Contact Person: _____
Address: _____
_____
City / State: _____ Zip/Postal Code: _____ Country: _____
Is this address the billing address? ❑ Yes ❑ No If no — indicate billing address and contact person with phone # here:

Conference Attendee: *(Please use a separate form for each person)*

First Name: _____ Last Name: _____
❑ I am a current TASH Member # _____ Preferred Badge Name: _____
Mailing Address _____
(if different from above) _____
City / State: _____ Zip/Postal Code: _____ Country _____
This address is ❑ home ❑ work ❑ school ❑ other _____ Please send my confirmation via ❑ email ❑ fax ❑ mail
Work Phone: _____ Home Phone: _____
Fax: _____ E mail: _____

TASH MEMBERSHIP:

❑ I am renewing my membership now Mem. # _____
❑ I am becoming a member now
If you are joining with 3 or more people from the same agency/organization/school take $20 off each person's applicable rate (must be in the same envelope)!

New And Renewing Members please select membership type (and add rate on other side) →

	International & Chapter	International Only	*Chapter Only
Individual	$103	$88	$33
Reduced Fee (circle one) Self-advocate/Parent/Student	$60	$45	$20
Family	$156	$136	$66
Organizational	$230	$200	$70
Lifetime	$1000	N/A	N/A

Attributes *(please circle all that apply)*

1. Administrator/Adult Services
2. Administrator/Education
3. Administrator/Other
4. Adult Service Provider/Staff
5. Advocate/Friend
6. Behavioral Specialist
7. Case Manager
8. Early Childhood Services
9. Educator/Teacher (K-12)
10. Government Personnel
11. Legal Services Provider
12. OT/PT
13. Parent/Family Member
14. Personal Assistant
15. Professional/Public Policy Advocate
16. Professor/Instructor (College/University)
17. Psychologist
18. Regular Education Teacher/Admin
19. Related Service Provider
20. Self-Advocate
21. Social Worker
22. Speech/Language Pathologist
23. Special Education Teacher
24. Support Specialist
25. Staff Development/Trainer
26. Student (College/University) List ID: _____
27. Supported Employment
28. Other _____

Accessibility and Additional Information Requests

❑ Sign Language Interpreter *Please indicate dates and times needed:* _____
❑ Please list any accessibility/ ADA accommodation needs: _____
Please note: information about accessibility at the hotel and surrounding vicinity will be available at the information desk on-site)
❑ Child Care/Youth Activities (Note: you must fill out an application in advance to register. Space is limited)
❑ Roommate Referral Program
❑ I would like a mentor to help me get acquainted with the TASH Conference while I am on-site
❑ I have been at the TASH Conference before and would agree to be a mentor to help others while on-site

* Chapter Only Membership does not qualify for reduced conference registration rates.

1999 TASH Conference Registration Payment Information

(Includes Opening Reception on 12/8/99 and Conference Activities 12/9–12/11/99)

TASH International Members:				
❑	Individual	$219		
❑	Student	$169		
❑	Parent (non-professional)	$ 49		
❑	Self-Advocate	$ 49		
❑	One Day Only ❑ Thurs ❑ Fri ❑ Sat	$119		
Non-Members:				
❑	Individual	$329		
❑	Student	$249		
❑	Parent (non-professional)	$ 79		
❑	Self-Advocate	$ 79		
❑	One Day Only ❑ Thurs ❑ Fri ❑ Sat	$169	**Enter Applicable Registration Cost Here →**	$

Discounts: (only one discount can be applied)		
❑ Earlybird Registrations (Must be sent with payment by September 24th)	Subtract $20	
❑ Groups of 5 or more registering for full conference (all registrations must be in the same envelope)	Subtract $20 per registrant	
❑ A direct support staff registering with a self-advocate	Subtract $50 from the staff person's registration	
❑ Two or members of the same school team registering together (ie: a special educator and a regular educator, or a regular educator and a paraeducator)	Subtract $50 per registrant	
	Enter Applicable Discount Here →	$ – ( )

After November 12, 1999 registrations will be on-site only and a $40.00 late fee must be added. To ensure that your registration process goes smoothly and to save money we encourage you to register early. If you do register on-site you must bring this form and payment or authorized PO with you at time of registration. **Enter Late Fee Here →**	$
Enter Total Conference Registration From Above Here →	$
New This Year – I would like to order the 1999 TASH Conference Yearbook *(available in June, 2000) Order with your registration and save $10.00* ~~$35.00~~ **$25.00 →**	$

TASH Tech Pre-conference Workshops (Wednesday, December 8, 1999)			
1st Choice: TASH Tech Session # _____ **2nd Choice:** TASH Tech Session # _____		**PLEASE BE SURE TO SPECIFY YOUR CHOICES!** (see page # 7)	
❑ TASH Member	$65.00		
❑ Non- Member	$85.00		
❑ Self-Advocate / Parent (Non-Professional)	$40.00	**Enter TASH Tech Fee Here →**	$
❑ TASH/NADD Symposium	$85.00	**Enter Symposium Fee Here →**	$

TASH Membership Dues from Front Side	$
Less $20.00 for three or more Joining as Tash Members from same Org/Agency/School	$ – ( )
Enter Total Membership Cost Here →	$
Additional donation to support a self advocate to attend the conference ❑ $5 ❑ $10 ❑ $20 ❑ Other	$
TOTAL AMOUNT ENCLOSED (add all applicable costs):	$

Payment Terms: Registration will not be accepted without payment by check, official purchase order, or credit card authorization. Please note that payment must be in U.S. Funds only. A $25.00 processing fee will be added to cancellations received after November 12, 1999, or for purchase orders not paid prior to the conference. **No refunds will be given for cancellations after November 12, 1999.** $25.00 fee for returned checks or unauthorized charges.

❑ Check Enclosed ❑ Purchase Order / State Voucher no. _____

❑ Visa ❑ MasterCard ❑ Discover Name on Card: _____

Card Number: _____ Exp. Date: _____ Signature: _____

Preliminary Schedule of TASH TECH Pre-Conference Workshops

TASH Tech Pre-conference Workshops are full day, in-depth sessions held on Wednesday, December 8, 1999. Registration is in addition to the full conference. Be sure to arrive early to participate in one of these dynamic and informative sessions!

T-1 Expanding & Deepening Relationships between Community Members & Adults with Developmental Disabilities

Angela Novak-Amado

Many agencies have begun working on building friendships between adults with disabilities and community members. This session will be for staff who have already initiated bridge-building efforts to: 1) share their experiences with others, 2) find avenues for going beyond barriers, and 3) discover ideas for expanding and deepening existing relationships.

T-2 Creating Field-Based Networks to Meet the Personnel Needs of Students with Significant Disabilities and Deaf-Blindness

Susan Bashinski, Margy Hornback, Donna Wickham, Gwen Beegle, Lynette Lacy

Kansas has implemented an innovative approach to providing exemplary education to students with significant disabilities in inclusive programs. The practices of this validated approach will describe an ongoing professional development model relying on excellent practicing teachers who consult with teacher teams around the state.

T-3 Tools for Working: SSI Work Incentives & Transition Age Youth

Sheila Fesko, John Butterworth, Vicki Brooke, Ellie Emanuel, Helena Hoas, William Halloran

Representatives from the Work Incentives Transition Network will provide participants with content material on the SSI program, the impact of working on SSI benefits, creative use of the work incentives to advance career goals and self-determination, and the role of schools in addressing SSI needs.

T-4 Creating and Maintaining Inclusive Learning Communities: Community, Curriculum and Teacher Inquiry

Mary Fisher, Mara Sapon-Shevin, Lucille Zeph

This interactive workshop will address the three essential components of inclusive learning communities: 1) community-building, 2) effective current and emerging practices in general education curriculum and instruction, and 3) reflective practice and teacher inquiry. The presenters will help to bridge the gap between research (or the ideal) and practice.

T-5 Functional-Contextual Assessment and Portfolio Design

Mary Fitzgerald, Susan Catlett, Eve Cugini, Charlene Comstock-Galagan, Sharon Lynch

This highly interactive session will explore the process of functional-contextual assessment as it relates to evaluation procedures under IDEA 1997. The process emphasizes a team approach (including parents), careful examination of current data, and data collection strategies that yield meaningful information which links to appropriate IEPs. Participants will also learn about and interact with student portfolios designed by parents.

T-6 Emergency Management

Gary Lavigna

When punishment is no longer used to manage behavior, people ask, "What do we do when the behavior occurs?" "What do we do in a crisis?" This seminar will provide an overview of emergency management and reactive strategies that might be used as part of a complete support plan.

T-7 Whole Brain Learning: Inclusive Academics, Music & Games

Robin Smith, Kate Farrar

This highly participatory workshop will emphasize use of multiple intelligences to enhance academic and social engagement and establish a competence-oriented learning community. Participants will experience music, body sculpture, and kinesthetic games to support academics in inclusive classrooms along with other approaches that support "whole brain" or "brain compatible" learning. The facilitators will discuss applications at all grade levels.

T-8 Developing Augmentative Communication Systems to Support Participation in General Education Classrooms

Rae Sonnenmeier, Michael McSheehan

Developing an augmentative communication system within an inclusive educational setting requires a thoughtful process to ensure that a stabilized communication system is not a prerequisite to being included. The phases of developing such a system, including considering the features of technology, and selecting vocabulary to increase curricular and social participation in general classrooms will be presented. This session will include discussion, interactive problem solving, exploration of technology, and personal stories.

T-9 Including Students with Disabilities as Fully Participating Members of the High School Community

Carol Tashie, Mary Schuh, Jeff Strully

Why students with disabilities should spend their high school career with all peers and strategies for overcoming obstacles that cause students to spend time away from typical peers will be discussed. What students should be learning in classes, after-school, weekends, and the transition to jobs will be discussed.

T-10 Organizing for Disability Rights and Inclusion

Steve Taylor, Bonnie Shoultz, and Others

This workshop will examine a range of grassroots community organizing strategies that people with disabilities, family members, and advocates can use to promote the full participation of people with disabilities in community life. Topics to be discussed include: building coalitions with disability and non-disability groups, developing position statements, sponsoring public forums and other actions, working with the media, organizing petition drives and letter-writing campaigns, and other strategies.

T-11 The Behavior-Communication Link

Kim Davis, Susan Dixon

Behavior is often overlooked as a legitimate means of communication. This workshop will provide information to families and individuals who support people with disabilities to build an understanding of how different behaviors are communicative, to understand what their messages might be and how to begin to interpret those messages.

T-12 Civil Rights, Decision-Making and Guardianship: Melding TASH Values with Best Practices

John Hoyle, Kathleen Harris, Joel Welber, Sally Burton-Hoyle, Patricia Dudek, Mayer Shevin

With the establishment of guardianship for individuals with disabilities, their ability to make decisions about their own lives has frequently been taken away. This workshop will focus on a number of preferable alternatives to support all people at risk including individuals with the most decision-making support needs. Discussion will include best practices in alternatives to legal guardianship, some recent court decisions, and philosophical debate surrounding self-determination and choice-making for people who are at risk of losing their right to make their own decisions.

T-13 IDEA: What Parents and Advocates Need to Know

Dixie Jordan

Join the Co-Director of the FAPE Program at the PACER Center to discuss IDEA following its 1997 reauthorization and newly released regulations. The workshop is organized around the six principles of IDEA '97: a free and appropriate public education; appropriate evaluation; Individualized Education Program (IEP) development; least restrictive environment; parent and student rights in decision-making; and due process procedures.

Look for additional TASH Techs in the Conference Brochure and future issues of the TASH Newsletter!

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Students Talk About Their Roles in Transition Planning

BY COLLEEN THOMA and MICHAEL WEHMEYER

"I just want to say that having a disability isn't easy, especially at the age of eighteen. It's basically hard because you want to become something in life and sometimes people won't let you. The people that you love the most will want to help you and you think your life is coming to an end because you don't want to hurt yourself, and you don't want to hurt your parents. I think this is the hardest thing about being a teenager, being trapped."
Kathy, age 18

Kathy expresses the fears felt by many students with disabilities as they prepare to leave high school. They fear that the visions they have for their adult lives are not only different from the expectations of their parents, but that pursuing these visions will cause pain for those about whom they care deeply. Students with disabilities have many adults who work with them to help make plans for this important transition, including their parents, teachers, school administrators, provider agency staff, and others. Some of these people, like parents and teachers, have long-standing relationships with students. Others come to the table with little or no direct knowledge of the student. Whatever their direct or indirect knowledge about the student, this group is charged with supporting the student in working toward developing and attaining a vision for an adult life. How can this be accomplished? This article will share the suggestions and recommendations made by students who were part of this process.

Overview

Although federal law regulating the education of students with disabilities has always indicated that students should be members of the educational planning team "whenever appropriate," the unfortunate reality is that for far too many students, others interpreted "whenever appropriate" as never. Such meetings were, by and large, times when adults would come together to discuss student deficits and remediation strategies and to make decisions for the student. In the last decade there have been significant changes in the IDEA that have compelled educators and parents to rethink the role of students in the educational planning process. In addition to requiring that transition services be provided for students aged 16 and older, the 1990 amendments to the IDEA also mandated student-involvement in transition planning by stating that needed transition services must be based on student preferences and interests. While the IDEA leaves the statutory language regarding student involvement in educational planning meetings at the rather ambivalent "when appropriate," the regulations regarding student involvement in transition planning are quite clear and unambiguous. The regulations state that if one of the purposes of the meeting is to consider transition services, then schools must invite the student [Sec. 300.344(c)]. The regulations rightly point out that "for all students who are 16 years or older, one of the purposes of the annual meeting will always be the planning of transition services, since transition services are a required component of the IEP for these students" (Sec. 300.344, Note 2). In other words, schools must invite all students aged 16 and over to planning meetings and decisions made about students' transition services must be based on students' preferences and interests.

The 1997 amendments added the further requirement that schools assist students to understand their rights and responsibilities and be informed of the imminent transfer of those rights, including the right to give informed consent, not less than one year prior to their 18th birthday. Given the student involvement language in IDEA, the impetus provided by the self-determination model demonstration projects funded by OSEP in the

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Students Talk About Their Roles in Transition Planning

Continued from page 8

1990s, and the 'age of majority' language in IDEA '97, the legislative and policy impetus to involve students in their own transition planning is considerable. As illustrated by the comments of Kathy at the beginning of this article, however, putting such policy mandates into practice is complicated.

What can teachers do to assure that students are not only present at their own meetings, but that they are actively involved in making choices for themselves? The simplest answer is to **ask the student for input.**

> ***"I would first of all ask, 'What subjects would you like?' Not what other people want, but YOU decide what you want. I want to make my own choices, and it seems like now that most of my family is making choices for me, in how much I should eat and when should I graduate, what jobs they want me to have. I want to choose all of these for myself. Not what my friends or my family want me to do. I know they're trying to help me. I really love them dearly and I know they're trying to help me, but they also have to understand how I feel."***
> **Kathy, age 18**

Just asking students for their opinions during transition planning meetings is not enough preparation for most students to think about and report their preferences. There are strategies that can be employed prior to such meetings, and throughout the school year, to prepare for these planning meetings. Teachers, parents, and other advocates need to **prepare students for their participation.**

> ***"Before meetings, my mother and me, we talked about what I wanted to do with my life, where I want to live, what I want to do for work. Then we practiced what I was going to tell people at the meeting."***
> **Duane, age 20**

Another strategy that supports student involvement in their transition planning meetings is to **change the format of the meetings so students have more opportunities to participate.** Many articles that address best practice procedures in transition planning include suggestions for utilizing person-centered meeting formats. One teacher points to the need for a change in format that would allow students to have a greater voice in planning for their own futures:

Students are present for the meetings, but that's about it. Right now, we're stuck in a format where the individual transition plan is almost a checklist. The transition plans miss the boat of truly reflecting a student's interests. But the format is quick and convenient. Ideally, I would like to walk into the meeting with a blank sheet of paper and say to the student, "What do you want to be when you grow up?" And then, whatever the answer is, say, okay, now what do we need to do to get there? What do we need to do in school, in the community, on the job?

Elaine, another high school student, discussed the fact that opportunities to try new things can help her make better decisions for the future. This is another strategy that can support student self-determination in transition planning: **expose students to many different opportunities, including career exploration, to help them make informed decisions and goals for their futures.**

> ***"I want to try new things. So before I get out of school then I can make up my mind on what I want to do."*** **Elaine, age 19**

Kathy pointed to the need to provide experiences and opportunities that reflect the student's preferences and interests, too. This strategy encourages teachers to **provide a multitude of opportunities to make informed choices, focusing foremost on those opportunities that are of interest to the student.** Not only do students need to learn to make their own choices and decisions, they have to learn to express them, and deal with the reactions of others. For many teenagers, this can be

> ***"We, as a team, with the job coaches and my sister and my parents, have been helping me gain experience, they have been helping me with adult decisions. I feel kind of pressured by mom because she wants me to have certain jobs that she thinks I might like. And I tried those different jobs and they don't suit me. ...my heart says that my dream job is in entertainment."***
> **Kathy, age 18**

difficult. It can be even more difficult for students with disabilities who often are more dependent on their parents than teenagers without disabilities. Teachers

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Students Talk About Their Roles in Transition Planning

Continued from page 9

need to **find ways to help students deal with the emotional aspects of making their own choices and choosing a greater degree of independence.** Kathy talked about this in great detail in the quote in the beginning of the article. Another student also addresses this issue:

> ***"They say that I will live in a group home after I graduate, but I don't want to. I want to stay at home with my mother until I get my own place. But what do I do? They say that if it doesn't work at the group home, I could come back home. I wonder what they mean by doesn't work out? Why won't they listen to me?"* James, age 18**

Not all students are able to clearly articulate their thoughts through verbal communication. Most special educators have students in their classrooms who have limited or no speech and for whom augmentative and/or alternative forms of communication have not been successfully obtained. Teachers and parents often feel that determining the preferences and interests of these individuals is very difficult, if not impossible. Rachel is a high school student who communicates in one-word utterances and/or gestures. Her mother has been responsible for sharing her interpretations of Rachel's preferences and interests for most of Rachel's life. One strategy for supporting student self-determination is to more fully **investigate alternative means of communication and to incorporate these into the transition IEP process.** This will help the student learn alternative means of communicating preferences and interests in a functional way. Rachel's mother talks about her fears of being responsible for communicating Rachel's preferences and interests in transition planning meetings:

"It would be nice if Rachel could verbalize exactly what she wants. It wouldn't be such a burden, not burden, but challenge. It is a heavy load because you've got another individual here that has every right to be in a situation that makes her happy, but again all you have to go on is Rachel's personality, knowing what makes her happy and what doesn't make her happy. Knowing what situations bring her confusion and what situations she just walks right into and is her social self. So you really do get a pretty good idea of what's going to be workable and what's not. At the same time, being a parent, I'm sure I'm overprotective."

Curtis is another student who receives special education in high school. He planned to attend college after high school, but had difficulty in finding transition team members who could help make his plans a reality. An important strategy for preparing students to be self-advocates is to **teach them about the laws that govern supports and services to which they may be entitled.**

> ***"You have to be knowledgeable and you have to be pushy. You have to know your rights and if it's within reason, you just have to push for all of the things to be in place. Because the professionals do not all know what they are talking about."* Curtis, age 18**

If the student is unable to make his or her voice heard, or if the transition planning team is not sure that such preferences are "realistic," it is important to find someone who is "visionary."

Find the "why not" person who can help find ways to make the student's dreams and visions a reality.

Kathy's mother spoke of this, saying:

"What it really took was someone who finally said 'Why not?' when the discussion about Kathy earning her high school diploma came up once again at a case conference. This set the wheels in motion and Kathy got onto the "diploma track" after that. The job coach who started working with Kathy toward the end of this year also said, 'Why not?' when we asked her about the possibility of finding a classroom assistant position for Kathy in an elementary school."

The importance of developing a transition planning process that both supports and encourages students to take responsibility for their own lives, to make goals and monitor their progress toward their goals and to express their preferences and visions to others is essential. It may be the only way that schools can impact poor outcomes for students with disabilities after they graduate from high school. We are naive if we believe that we can continue to develop plans that "have students' best interests at heart" if we fail to involve them, and/or ignore their opinions throughout the process. Students will find ways to assure that their preferences are heard and respected after high school, if not before. Duane, a senior high school student, had this to say when discussing his upcoming graduation:

> ***"I can't wait until I graduate because then I can quit this job and find me one that I want, without all of their 'meddling.'"* Duane, a high school senior**

Colleen Thoma is an Assistant Professor at the University of Nevada Las Vegas. Michael Wehmeyer is Assistant Director, Department of Research & Program Services, ARC National Headquarters.

Why Workshops Should Be Closed and Why People Should Work in the Community

BY LIZ OBERMAYER

Most self-advocates are concerned that not many people with disabilities have good jobs, but unfortunately this has not yet been seen as one of the priorities for some national and state self-advocacy groups. I think the reason is that people with disabilities don't believe they could or should have a "real" job. People are not encouraged to have jobs. Unfortunately, staff, parents, and professionals usually have low expectations about what people can do.

Gunnar Dybwad, a well-known leader in the disability rights field, said that this is the "most serious problem" in his eyes. He said that getting a "real" job will help with liberation beyond people's disability. I agree with Gunnar because I think jobs help people achieve the dignity they deserve. When people get a "real" job, they can contribute to society and then we feel like we belong in the community.

Why is it okay for a person with a disability to not work if they choose, and it is unacceptable for a person without a disability to not work? If you don't work, society looks down on you. I think society doesn't treat people with disabilities as a "whole" person.

Have you ever thought it was strange to see people with disabilities leaving their jobs at 3:00 in the afternoon? Most people without disabilities need to work an eight-hour day. When people leave at 3:00, it looks like they are in school rather than at a job. I think this is the case because staff don't think people with disabilities can work an eight-hour day, or staff don't have the same kind of expectations for people with disabilities as they have for themselves. Sometimes staff without disabilities want to leave at 3:00 too, so people with disabilities have to leave at that time regardless of whether they want to continue to work.

People with disabilities should be able to select jobs for themselves on the basis of their abilities and interests. People just need the right kind of support to do their jobs. If at all possible, the support should come from the job rather than a job coach or somewhere else. The reason is because it is more natural for co-workers to support each other than for an outsider to support the worker.

When I was in an office skills program, we came to work around 9:00 A.M. like everyone else, but we left at 3:00. At first I thought this was strange and I questioned them about this. I was told that 3:00 was the time that similar programs dismissed for the day.

In my job as a self-advocacy specialist at the Department of Mental Retardation in Massachusetts I asked my supervisor what would happen if I left every day at 3:00. I was told that I wouldn't be paid my full salary. The only other group of people that start their day at 9:00 and end at 3:00 are school children.

Why should adults that have disabilities have a schedule that kids follow? I think the reason is because people see individuals with disabilities as children. Many people with disabilities still work in workshops.

All people can have a "real" job, regardless of their disabilities. However, some people (including my own parents) don't believe this is the case. People with disabilities should be able to select jobs for themselves on the basis of their abilities and interests. For example, if someone is not interested in working outside with flowers, then working as a gardener or mowing lawns might not be a good job for this person. People just need the right kind of support to do their jobs. If at all possible, the support should come from the job rather than a job coach or somewhere else. The reason is because it is more natural for co-workers to support each other than for an outsider to support the worker.

People with disabilities want to be treated as much like people without labels as possible. For example, when I was working at the library, the majority of my support came from my co-workers. Now that I am at the Department of Mental Retardation, I insist on my support coming from the people I work with. This hasn't been so easy for my co-workers. It's funny that at first the support wasn't given so easily. The reason it's funny is because supporting people with disabilities is what the Department does.

Another reason why people should be able to have "real" jobs is because having "real" jobs can give people something worthwhile to do. It also can show to the world that people are people first, before their disabilities. We need to remember that people with disabilities have all kinds of different talents and interests.

Another question is why do we have to be in separate places or in separate jobs from people that don't have the label of a

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Why Workshops Should be Closed and Why People Should Work in the Community

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disability? Do people think they can catch our disability from being around us? Having people work in a workshop is another way of segregating people in a "them" or "us" category.

When I was working in an enclave in New Jersey, we had a "special" table where people with disabilities sat to do work. There was also someone that was hired by the agency to help us. This made me feel like people didn't trust me to do my work unsupervised and that I couldn't ask other co-workers to assist me. It didn't feel like a "real" job to me.

One of the biggest reasons people don't like to work in a workshop is that they don't earn a proper amount of pay. Most of the time people with disabilities don't even earn minimum wage. If an employer didn't pay people without disabilities the minimum wage, they would get into a lot of trouble for violating the law. Why can they get away with it when they are dealing with people with disabilities? Is the answer that people think they can take advantage of people with disabilities? Working "outside" of a workshop will also show the world that people with disabilities can earn a regular paycheck, pay taxes and make a "contribution" to society.

Most of my friends don't like to work in an environment that tells society that it's okay to treat them like children. Instead, they choose to sit home and watch television. This is another way that people with disabilities are seen to be in a different category than everyone else, because in this society people are expected to work when they are finished with school.

People with disabilities shouldn't be made to feel like they are different than anyone else. A fun part of working at a job is that you get to meet a lot of different people. I remember when I was working at a library, we used to have parties and I went out with friends for lunch once in a while. In my current job, we also have parties and I go out for lunch with my friends. I also enjoy talking to my office mate, Karen.

However, making friends and going out for social events isn't a job responsibility when you are hired. It is true that getting the job done needs to come first, but for some people socializing with co-workers is a very important part of a job. It makes working more pleasant.

The last point I want to make about why people with disabilities should not work in workshops -- and this is probably the most important reason -- is because people with disabilities have the right to work! I believe that to get a job people with disabilities need to believe this.

What will it take to close workshops?

"Everyone should be able to find a job that matches their skills and speed. People need to know they are going to get the kind of support they need to solve a problem, to develop their skills, and show that they have other qualities that are important to their employer."

First, I find that taking any kind of job is a risk. People with disabilities sometimes don't believe that they can work in a "real" job. I remember the first day that I worked at the library, my first "real" job, I questioned myself about whether I could really work there. Would I be successful? Would my co-workers be happy with my work? Would they take me seriously in my job? Would they like me? I didn't have the confidence in myself that I needed.

Everyone should be able to find a job that matches his/her skills and speed. People need to know they are going to get the kind of support they need to solve a problem, to develop their skills, and to show that they have other qualities that are important to their employer. For example, when I worked at the library I could not put away the books as fast as other people did, but I had the ability to accurately put the books away in the correct place. That was more important to my bosses than whether I could put the books away as fast someone else. They got to know me as a person who was capable of doing the job, rather than focusing on what I couldn't do.

Sometimes people feel that it is "safer" to work on the "inside," in a workshop, at the agency's front office, or in a work skills program. This may be because when you work in the agency or in a work skills program, it is harder for you to get fired. The service provider might be willing to give the person more than a couple of chances to improve. However, when have you a "real" job, people with disabilities may be worried that the employer will not be as patient with you and not accept that people just might need extra time to learn the job.

Soon after I started at the library my father met with the director. I felt like she thought my father expected her to show "partiality" toward me. That really embarrassed me because it looked like I couldn't handle my own job. How many of your parents have gone to meet your boss to talk about your job? Sometimes parents might feel safer and more secure to have their son or daughter employed

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in a workshop rather than in the community. Parents worry about the same things we get worried about. However, now that I have shown my parents that I can handle any problems or difficulties that come up in my job on my own, they have stepped back and don't interfere, but still offer me as much support as I want.

> **"If you are still not convinced that workshops and sheltered programs should be closed, I challenge you to spend some time in them. I would also encourage you to think about the amount of money people earn and decide if you could live on that wage."**

We need to help parents and family members feel comfortable knowing we can handle things for ourselves. They need to learn to let us take a chance rather than step in and help solve the issue every time. We need to tell our parents and other people that we need a chance to solve our problems ourselves - they don't need to do it for us! They can, however, "stand" by us for support.

Workshops only provide a few options, so this keeps people from learning and trying out different kinds of jobs and skills. In the program I was in, with the choices I was offered I couldn't imagine getting a job at all. The choices that I was given were things that I didn't want to do. Some of the options were to work in a greenhouse, on a farm, or in an office. Well, the office was somewhat interesting to me, but it wasn't really what I wanted to do.

If I was assertive and said that I didn't like any of the work options, my instructors could tell me that there was no job out there for me. This happens all the time. One of my friends stayed in the workshop longer then he wanted because he didn't think there were any other choices available to him.

People have to prove themselves to staff before they are willing to help you find a job in the community. Why should I have to prove myself, and people without disabilities don't? Is this really fair? Is this treating people with disabilities and people without disabilities as equals?

One of the other experiences I had in sheltered work environments was that I always worked with people with disabilities. I never had opportunities to learn from people who didn't have disabilities, nor could they learn from me. When I was in that environment I always felt like I was being "baby-sat." I felt like I didn't need that, and I was totally embarrassed by this treatment. I also feel like you waste your time at a workshop. Many times you are not doing anything more than sitting-around.

If my words still haven't convinced you that workshops and sheltered programs should be closed, I challenge you to spend some time in them. I also would encourage you to think about the amount of money people get paid and decide whether you could live on the pay. If we all work together to close the workshops and sheltered programs, maybe people with disabilities can work in an environment that they enjoy, earn a decent wage, and learn from the experience, too. In the self-advocacy movement we like to say, Together Everyone Achieves More. Let's do it together!

Liz Obermayer is a Self-advocacy Specialist with the Massachusetts Department of Mental Retardation, and Secretary of the TASH Executive Board.

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THE PROMISE AND PITFALLS OF THE WORKFORCE INVESTMENT ACT

BY MICHAEL CALLAHAN

Over the past fifteen years many of us on the employment side of TASH have been suggesting that natural and generic approaches represent preferred avenues for persons with significant disabilities to achieve meaningful jobs in the community. Apparently Congress was listening.

In the summer of 1998 Congress passed, and President Clinton signed, the Workforce Investment Act (WIA, PL 105-220). This sweeping labor law took its direction from the so-called "Republican Revolution" in 1994 and consolidated a number of federal employment programs, including Vocational Rehabilitation, into a single, comprehensive initiative designed to offer a single point of entry for all citizens who want to become employed. Four cabinet-level departments are required to participate in WIA, including the departments of Labor (DOL), Education (DOE), Health and Human Services (HHS, under the Community Services Block Grant) and Housing and Urban Development (HUD). Additionally, HHS, under Temporary Assistance for Needy Families (TANF), the Departments of Agriculture and Transportation, as well as Americorps, are encouraged to participate in the implementation of this act.

How does all this relate to the employment needs of persons with significant disabilities? At this point it's fair to say that the answer is unclear. However, the best route for successful inclusion into WIA is likely to be through the series of One-Stop Career Centers that are mandated by this legislation. This component of the act requires states to develop comprehensive employment centers in Service Delivery Areas (SDAs) representing geographic areas comprising 200,000 - 500,000 persons. One-Stop Career Centers are supposed to provide a single point of access to services leading to jobs and careers for all unemployed citizens.

WIA is driven by a set of principles that govern both the broader act and the one-stop system specifically. The overall direction set by WIA embraces the following principles:

Principles of the WIA:

- Providing universal access to all who want to work;
- Empowering individuals who use WIA's services;
- Streamlining services;
- Providing state and local flexibility;
- Increasing accountability to the user, taxpayer and system;
- Strengthening the role for local boards and private sector; and,
- Improving youth programs.

In addition to these seven principles embedded in the overall act, WIA charges One-Stop Career Centers with four elegantly simple directives:

I. Universality of access and services
II. Customer choice
III. Integration of services offered (blending, combining resources) and,
IV. Accountability for results by providers

Looked at through the values lens of an organization such as TASH, these principles seem more in keeping with our perspectives regarding the needs of persons with significant disabilities than most traditional, generic legislation. And even though the basic thrust of the legislation undoubtedly was not directed towards welcoming the people who TASH represents, the welcome mat is out. The challenge we face is whether to accept the implied invitation, to enter into these historically inadequate generic systems, or to focus on the disability-specific services that have gotten us to this point. The decision is not an easy one.

One-Stop Career Centers will be a part of a revamped state employment system that replaces the Job Training Partnership Act (JTPA) and blends each state's job service agency (from the Wagner-Peyser Act), with Adult Education, Vocational Rehabilitation and a laundry list of over fifteen other agencies that provide employment supports ranging from Job Corps participants to veterans to Native Americans. WIA allows for significant, indeed unprecedented, flexibility at the state and local level. The act requires the development of a statewide workforce board and a cadre of local workforce boards, one for each Service Delivery Area that contains a One-Stop Career Center. The Governor of each state has extensive powers in setting the particular course that each state will take, as well as appointing members to the statewide board. There are relatively few sweeping federal mandates within WIA. Rather the law

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provides a general direction and national intent, leaving the specifics to the states.

Each SDA will be managed by a Local Workforce Board whose membership is selected by a local elected official (LEO). In the case of multiple LEO's, a compromise working agreement must be submitted to the Statewide Workforce Board. Participation by entities representing persons with disabilities is required for both local and state boards, but selection is not guaranteed. Private sector employers must comprise at least "one plus fifty percent" of each workforce board. These boards will largely determine the degree to which one-stop centers will seek to recruit, welcome and effectively serve persons with significant disabilities.

The Reality

It takes energy and resources to be present at the table as the decisions regarding the shape of local One-Stop Centers are made. At this point, two of the most widely-utilized sources of funding for employment for the persons that TASH represents, vocational rehabilitation (VR) and developmental disabilities (DD) state agencies, are cautiously considering their roles. Vocational rehabilitation is a required partner of the one-stop system. However, at this point, VR agencies in many states have chosen to present themselves as an alternative to the One-Stop system — offering services when centers are unable to meet the needs of certain applicants with disabilities — as opposed to providing the additional capacity necessary to make the generic system work seamlessly for all persons with disabilities.

In fact, inclusion is the central theme of the promise of WIA. Congress, whether it intended to or not, has provided us with the legislative structure to move aggressively from a disability-focused employment system to a generic, natural approach.

State DD agencies are even further from the table. Since DD is not a required partner of the one-stop system, most state agencies have virtually ignored the development phase of WIA. It can only be assumed that unless there is a noticeable turn-around, DD state agencies will be left out of local and state workforce boards.

One-Stops are charged with providing each applicant access to a set of "core services." Those services include:

a. Eligibility determination for adults, youth and dislocated workers;

b. Outreach, intake and orientation to one-stop services;

c. Skills assessment (which can include non-assessment based discovery);

d. Job search assistance and career counseling;

e. Information on provider's performance and program costs;

f. Disclosure of the local workforce area's performance measures;

g. Information on supportive services such as child care and transportation;

h. Assistance in filing unemployment compensation claims;

i. Establishing eligibility for Welfare-to-Work services; and,

j. Follow up services after employment.

An important difference between WIA and the Job Training Partnership Act involves the use of Individualized Training Accounts (ITAs) in the new act to pay for employment programs and services. Rather than having the Private Industry Council (PIC) under the JTPA contract with employment training programs and slot applicants to those pre-selected providers, WIA One-Stops offer the opportunity for applicants to take their ITA vouchers to providers of their choice for services.

The Promise is Inclusion

Imagine a young person with a significant disability graduating from a school anywhere in our country and being able to go to the local One-Stop Career Center to become successfully employed. Imagine a person who has the chance to leave a state institution receiving access to personalized employment planning and job development representation from a One-Stop Center. Imagine an adult with significant multiple disabilities, along with his or her family, going to a One-Stop Center to receive assistance in developing a personal budget to pay for the employment services that will allow them to leave a workshop or day center. These images alone represent a sufficient reason to fight for inclusion into generic employment services just as TASH has fought for inclusion in regular schools across the U.S.

In fact, inclusion is the central theme of the promise of WIA. Congress, whether it intended to or not, has provided us with the legislative structure to move aggressively from a disability-focused employment system to a generic, natural approach. But the mandates are few. The promise of this new law can easily pass us by as the local deals and structures are set. States have until April 1, 2000, to present plans for implementation of their One-Stop systems and all states must have a fully operational network of One-Stops in place by July 1,

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2000. This means that TASH members and others interested in the full inclusion of persons with disabilities within this system have less than a year to get to the table and to assure that access is offered. Some states may already have One-Stop Centers as a result of a pilot demonstration initiated by DOL in the mid '90's. These sites may be grandfathered into the new system required by WIA, but they still must meet the general intent and direction of the legislation.

> School inclusion raises many of the same concerns that are voiced in employment such as how to balance the need for specialized services with the desire to achieve access to natural, generic environments and services. While concerns such as these are valid, they have not stifled TASH's advocacy to offer the benefits of full inclusion to all students. The same values must be embraced regarding access to employment.

Even though it is accurate to say that the underlying values of WIA are based more on streamlining, minimizing and economizing government services than on meeting the needs of all persons in the community, the stated values within the legislation provide us with a sufficient framework to shape this emerging system in a way that can become a single point of access to employment services for all. However, just as special education services in schools have had to rethink and re-form themselves to adjust to the demands of inclusion, so also will the current disability-focused employment structures of vocational rehabilitation and developmental disability agencies. It would probably be accurate to state that less than one percent of all persons that TASH represents have successfully used the generic job service office to become employed. It will require both in-depth consideration and aggressive action by VR and DD agencies, as well as by advocacy organizations such as TASH, to shift this reality towards inclusion.

An easily overlooked promise of WIA, especially for those of us who are focused within the disability arena, is the wealth of resources that might exist within the current and future One-Stop Centers. Small business incubation centers, employee support groups, carpool and transportation co-ops and other similar services are available in many areas. It is our responsibility to assist these resources to become responsive to the needs of non-traditional applicants.

The Pitfalls of WIA

First, there is no guarantee that the kind of directed effort indicated above will successfully open the generic employment system to persons with significant disabilities. Since we have only so much energy and resources, there is a valid caution that could be raised concerning the degree of effort we can expend in such a risky venture. And beyond our own energy, what might the fallout be from our funders who are cautiously avoiding full participation in the development of WIA? Many state vocational rehabilitation agencies are deeply concerned that the end result of WIA is that they will be so assimilated into the generic system that VR will cease to exist. This concern for survival can easily result in battle lines being drawn between state or local VR offices and those who advocate for an inclusive system.

Developmental Disabilities agencies within states can also cloud the issue. Since most have remained well away from the initial implementation efforts, the clear message to providers of employment services for persons with significant disabilities is that WIA does not concern them. This message implies that we will continue to do business as usual and that there is no need for providers to seek funding or relationships within a One-Stop Center.

A further pitfall of WIA involves the reality of devolution of power. This is perhaps the first example in the disability field of Congress' intent to transfer power and decision-making to the state and local level. Gains and examples of successes in one state, or even one region within a state, might vary significantly with others nearby. Since the structure and services of each One-Stop will be locally determined we will not be able to easily cite exemplary services in a promising area as an overall model or strategy. Success will require local effort within one region, one state at a time.

Another concern of WIA is the question of whether effective and individualized services can be offered within a generic structure such as a One-Stop. The Department of Labor has always been focused on macro-economic issues and national statistics. The needs and concerns of individuals have a low priority at best. We know that the best outcomes for the persons we represent are achieved through an individualized, person-directed approach; however, it is unclear whether One-Stops will be willing to work with one person at a time.

Finally, there is the pitfall of WIA just becoming another hollow promise to persons with significant disabilities and their families. One could easily imagine a family effort to access services within a One-Stop Center resulting in even deeper fatigue and disappointment. The current generic system simply does not intend or even attempt to effectively serve the persons that TASH represents. Why should we think that the new system will be any better?

Reflections on WIA

When TASH began to solidify its direction regarding school inclusion, it would be fair to say that regular schools had a similar track record of serving persons

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with significant disabilities as the generic employment system does today. However, after a decade of a focused initiative on full inclusion, services have shifted dramatically across the country for the better. School inclusion raises many of the same concerns that are voiced in employment such as how to balance the need for specialized services with the desire to achieve access to natural, generic environments and services. While concerns such as these are valid, they have not stifled TASH's advocacy to offer the benefits of full inclusion to all students. The same values must be embraced regarding access to employment.

In addition to the compatibility of values between inclusion issues in schools and in employment, there is another somewhat sobering rationale for TASH members to become involved in WIA — the possibility of promoting segregated services if we do not become involved. The act allows One-Stop Centers to treat "special participant populations that face multiple barriers to employment" differently from other applicants. Of course its easy to see the people TASH represents included in this "special population." One-Stops may contract with "community based organizations or other private organizations" to provide a "training services program"[PL105-220, Sec. 134, (d), 4,(G), ii, III]. The best case scenario for this circumstance would be that a supported employment agency would receive a disability-focused contract to provide services. The worst case would be if a workshop or other segregated entity received the funds for extended "pre-employment" training.

Anytime a radical shift, such as using generic employment systems for person with significant disabilities, is suggested people look for examples of success. In July of 1998, United Cerebral Palsy Associations was awarded a three-year demonstration grant to examine the feasibility of welcoming persons with significant physical disabilities to existing One-Stop Centers in Detroit and Denver. This project, now nearing the end of its first year of implementation, is currently serving 38 individuals within the two sites. The project features:

a) individualizing the core services offered by One-Stops to include a person-centered discovery and planning approach;

b) assistance in developing a personal budget;

c) blended funding from a variety of sources such as One-Stop funds, VR, DD, PASS plans, Medicaid Waiver and other resources; and

d) contracting with providers of one's choice to access the employment services needed to accomplish personal goals.

This experience has led us to offer the following recommendations concerning WIA:

Learn about WIA by reading the law, accessing the DOL web site (www.doleta.gov) and talking to local employment officials about local plans.

Find out who is responsible for implementing WIA within your state and ask about participation by persons with disabilities and provider and advocacy agencies on state and local workforce boards. Try to become appointed to your board or advocate for someone consistent with TASH values to become appointed.

Encourage your state's VR and DD agencies to participate in state and local workforce boards in a way that would allow persons with significant disabilities to utilize One-Stop Centers for employment in a seamless manner, without being bounced back and forth among agencies for funding. It should be possible for all persons with disabilities to access a One-Stop for services without being handed off from one entity to the next for funding and outcomes.

Encourage provider agencies to contact their local workforce boards and offer to provide "soft-skill, on-the-job-training and customized" training services for persons with more significant disabilities. These terms are contained in the WIA legislation and represent the likely avenues for applicants to avoid becoming slotted in classroom/curricular training programs as opposed to individualized employment services.

Partner with an interested person with a significant disability (and family members, as appropriate) in a one person effort to negotiate an individualized employment outcome from a One-Stop Center. This is probably the most effective way to move this system.

Engage your state's VR and DD agencies in dialogue to help them consider valued, yet distinct, roles with the One-Stop system and to encourage them to participate in a series of demonstrations to discover ways to include the persons we represent.

Take the initiative, either personally or through your TASH chapter, to offer information, suggestions and advocacy to your local workforce board and to the One-Stop operator.

You may contact UCPA's One-Stop to Success Project Co-directors: Michael Callahan and Norciva Shumpert, at 228-497-6999; e-mail, MiCallahan @aol.com, Civa@aol.com; or visit UCPA's web site at www.UCPA.org.
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Access to Outdoor Recreation: An Update on the Regulatory Negotiation Committee

BY CYNTHIA BURKHOUR

The Regulatory Negotiation Committee on Accessibility in Outdoor Developed Areas is the group of negotiators from across the country representing people with disabilities and providers of outdoor recreation opportunities. The Committee has been charged by the U.S. Access Board with the task of developing the accessibility design rules for outdoor picnic areas including campgrounds, trails, and beaches for implementation under the Americans with Disabilities Act.

The Committee has reached tentative agreement on the technical (what it will look like) and scoping (when and how it will be done) provisions governing picnicing and camping areas. Accessible design of the elements that support these activities will be required.

For example tables, fire rings, cooking grills, benches, camping pads and hook-ups, information signs, trash receptacles, etc. will meet criteria that specify reach ranges, heights, transfer supports, clear spaces, and maneuvering spaces that make the element accessible to and usable by individuals with disabilities. The group has also agreed on how many elements (i.e. tables, fire rings and the like) should meet the technical design criteria and where they shall be located throughout a site. Many of these elements are already "universally designed" in ways that make them easier to use by all people. Choosing those designs will create a greater amount of access for all visitors.

The Committee is now struggling with the specifics of trail and beach access and is meeting to resolve some philosophical and practical design problems that make accessible development a challenging process.

Accessibility Guidelines for Play Facilities

Accessible playgrounds open up a whole new world of opportunities to children with disabilities. All kids can play together, be creative, test their abilities, and become friends. The Access Board's Regulatory Negotiation Committee on Accessibility Guidelines for Play Facilities issued its final report in July 1997. Since then, the Access Board has developed the proposed final rule, solicited and analyzed public comment, and is now preparing the final rule to be signed into law in the near future.

The Accessibility Guidelines for Play Facilities establishes the design parameters for all newly constructed and altered play areas covered by the ADA.

The technical provisions describe the design requirements for accessible play equipment and facilities, essentially "what it will look like." The scoping provisions describe the circumstances which dictate compliance, essentially "when and how" the technical provisions must be met.

The design guidelines address several key concepts, including:

- On small to medium structures with less than 20 elevated play components, half of the elevated play components must be accessible and reachable by ramp or transfer system, and on larger systems with 20 or more elevated play components, 25% must be reached by ramp or transfer system.
- An accessible route is required to, on, through and off play structures and must connect the accessible play components throughout the play area.
- Accessible play components must meet specific design parameters which specify maneuvering space, clear floor or ground space, reach ranges, transferable height of play componennts, and transfer supports.
- There is a requirement for accessible surfacing that also meets safety requirements connecting entrance and exit points from play components and play structures.

This is just a sample of the kinds of requirements addressed in the proposed final rule governing accessible playgrounds. For a copy of the final report, or to receive a more complete update on the progress of the Regulatory Negotiation Committee's work as it pertains to outdoor developed areas, please contact the Access Board by calling (202) 272-5434.

Cindy Burkhour is an Inclusive Recreation Consultant based in Jenison, Michigan and is Coordinator of TASH's Leisure & Recreation Committee.

For more information on inclusive recreation programs or if you'd like to participate on the Leisure & Recreation Committee, contact Cindy at AccessRecreationGroup@juno.com.

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Sometimes State Agencies Do the Right Thing. . .

BY THE TASH COMMITTEE ON EMPLOYMENT AND TRANSITION

In 1994, persons with disabilities, advocates, employment providers, state agency personnel and a few politicians met in Austin, Texas for a Summit on Supported Employment. It was a meeting much like countless other such meetings that have been held across the country during this decade to promote the benefits and successes of working in the community. However, this was not to be just another state conference. Due to the fact that the state comptroller was asked to convene the meeting, and the chair of the board of the Texas Department of Mental Health and Mental Retardation (TDMHMR) wanted to participate along with two additional board members, the results of this meeting were far-reaching.

The outcome of this meeting was a challenge to the state to shift the values that underpinned the resources spent for vocational services. It was determined at the summit that there was a significant disincentive to persons with disabilities who wanted a job of their choice in the community. A vision statement was drafted that urged the following: *"The State of Texas shall assure that all Texans with disabilities have the opportunity and supports necessary to work in individualized, competitive employment in the community and have choices about their work and careers."*

Within a year not only had the Board of TDMHMR voted to support the resolution adopted by the summit, the state's human service code was amended to reflect these values. The Board Resolution committed Texas to a five-year effort that requires that 50% of all persons with mental retardation receiving state general funds be employed in individualized, paying jobs of their choice by the year 2000. This unprecedented plan is currently in the latter part of the fourth year of implementation. The state has reached the 42% mark of that 50% goal. This represents a 5% increase over the target rate set by service authorities across the state. It appears that the overall goal will be achieved.

The Employment and Transition Committee of TASH commends TDMHMR for its commitment to choice and individualized community employment.

A Aspen School District

Aspen, Colorado

Seeking a part-time, high school Inclusion Teacher beginning in the Fall of 1999. Responsibilities include making curricular modifications, providing community-based instruction and job skills training, consulting with teachers regarding curricular accommodations, and supervising paraprofessionals.

For additional information contact Morgen at (970) 925-8057, ext. 573 or Lisa at (970) 925-2972, ext. 435.

For an application, contact Ginny Haberman at (970) 925-3460.

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Doctoral Assistanceship in Special Eduction, Specialization in Significant Disabilities at the University of Pittsburgh, Department of Instruction and Learning, Program in Special Education

Opportunities to participate in public school-based research and development and college teaching. Assistanceship includes salary and tuition.

Master's degree in Special Education or related field, certification in Special Education and minimum three years successful public school teaching (preferably at the secondary level) required.

To inquire contact Steven R. Lyon, Ph.D., Associate Professor, Special Education, University of Pittsburgh, 4H01 Forbes Quadrangle, 230 South Bouquet Street, Pittsburgh, PA 15260; Phone: (412) 648-7203; Fax: (412) 648-7081; E-mail: lyon@fs1.sched.pitt.edu; or Visit our web site at www.dil.sched.pitt.edu

Ensuring Access, Equity and Quality for Students with Disabilities in School-to-Work Systems

BY EILEEN L. ORDOVER

Students with disabilities are in dire need of the high quality educational opportunities that properly designed school-to-work systems can provide. Twenty-five years after the passage of what is now called IDEA, students with disabilities all too often are subjected to low expectations, poor education and poor outcomes, including segregation in low-track courses, high dropout rates, low rates of participation in post-secondary education and low employment rates. Equitable participation in the same high quality school-to-work programs mandated and created for all students is a significant part of the solution to these ills.

The School-to-Work Opportunities Act of 1994 is intended to prompt the creation of a universal, high-quality, school-to-work transition system that enables *all* students in the United States to successfully enter the workplace and pursue further education. The Act seeks to improve the knowledge and skills of all American youths by emphasizing the critical importance of integrating academic and occupational learning, integrating school-based and work-based learning, and building effective linkages and partnerships between secondary and post-secondary education. It is premised on recognition of the importance of using the high school years to equip youth with the complex knowledge, skills and abilities they will need if they are to have meaningful life options for good jobs, further training, and higher education.

Ensuring Access, Equity and Quality for Students with Disabilities in School-to-Work Systems is a book about merging quality and equity in school-to-work systems: the development of high quality programs for all students, and equity in those programs for youth with disabilities. By "quality," we mean programs that prepare students for careers, and are designed to meet the same high academic standards set by the state for all students. Quality programs integrate academic and occupational learning, provide strong understanding and experience in all aspects of an industry, develop higher order skills and prepare students for post-secondary education. Quality programs also empower students to make career and life choices by giving them the flexibility and transferrable skills they will need to cope with labor market changes and technological change, and to develop new education and career goals over time. By equity, or equitable participation, we mean full and meaningful participation by students with disabilities in the high quality programs created for *all* students.

The book begins with an overview of five key federal laws: The School-to-Work Opportunities Act, the Carl Perkins Vocational and Technical Education Act, Section 504 of the Rehabilitation Act of 1978, the Americans with Disabilities Act ("ADA") and the Individuals with Disabilities Education Act ("IDEA"). Taken together, they form the infrastructure for quality for all youth and equity for youth with disabilities. The School-to-Work Opportunities Act and the Perkins Act, which virtually all states are using to underwrite the cost of school-to-work programs, incorporate standards designed to ensure that students receive high quality programs integrating academic and vocational learning. Both Acts also expect that *all* students, including students with disabilities, will have equal and meaningful access to the high quality programs they mandate. Section 504 and the ADA, civil rights laws prohibiting discrimination on the basis of disability, independently require equity for students with disabilities in the programs and systems the School-to-Work and Perkins Acts create. IDEA, amended in 1997 to more explicitly address the right of students with disabilities to education programs based upon high expectations and attainment of the same high standards set for their non-disabled peers, provides critical tools for ensuring quality and equity in the school-to-work programs designed for all students.

Ensuring Access, Equity and Quality also:

- Explores the meaning of "quality" in the twin themes of quality and equity;
- Introduces three critical, guiding principles that flow from the convergence of the School-to-Work Act, Perkins, Section 504, the ADA and IDEA;
- Examines in detail how IDEA can be used as a tool for making real the right to equitable participation in the high quality school-to-work programs created for all students;
- Provides a guide to the systemic data collection, monitoring and evaluation activities necessary to ensure quality and equity for students with disabilities, and for all students.

Throughout, the discussion considers policy and practice implications as well as legal rights and responsibilities for policymakers, administrators and those educators and employers responsible for implementing school-to-work systems.

The above represents a brief overview of the new publication, Ensuring Access, Equity and Quality for Students with Disabilities in School-to-Work Systems: A Guide to Federal Law and Policies. Written by Eileen L. Ordover and Leslie T. Annexstein, and published by the Center for Law and Education and the National Transition Network, this just-released book can be purchased by contacting: Center for Law and Education, Publications Office, 1875 Connecticut Avenue, N.W., Washington, D.C. 20009, (Phone) 202-462-7688, (Fax) 202-462-7687.

National Plan for Training Personnel to Serve Children with Blindness and Low Vision

Work is underway to address the need for appropriate educational services for our children and youth with blindness and low vision. A special national project is focusing on the needs we face, moving into the next millenium, to train an adequate number of teachers and Orientation and Mobility Specialists so that all children receive adequate services. This is particularly relevant in rural communities.

The National Plan for Training Personnel to Serve Children with Blindness and Low Vision is a two-year project funded by a U.S. Department of Education Office of Special Education grant to the Council for Exceptional Children (Division on Visual Impairments). CEC is working in partnership with other organizations and a large group of stakeholders to study the issue and draw up a plan for the nation.

This plan will present strategies to meet the need for appropriately trained professionals in numbers that will both relieve the shortage and move us forward into the next century. The national plan (now available as a draft for review and comment) will highlight strategies to provide a full contingent of services to every school and educational setting serving children who are blind, deaf-blind or have low vision. The national strategic plan will be used to improve our children's literacy and enhance the quality of education received by our young children and school-aged youth.

The plan will be completed and available in the Fall of 1999. To obtain a copy of the draft national plan, contact:

Colleen McNerney, Project Coordinator, National Plan for Training Personnel to Serve Children with Blindness and Low Vision, Council for Exceptional Children, 1920 Association Drive, Reston, VA 20191, (703) 264-9456, E-mail: colleenm@cec.sped.org

Inter-American Institute on Disability (IID) seeks two Volunteer Interns

Excellent opportunity to develop and improve international organizational development and networking skills!

IID, a non-profit entity founded and managed by people with disabilities to empower self-advocates and their families in the Inter-American region and Spanish and Portuguese-speaking countries of Europe and Africa, seeks two volunteer interns with computer experience and excellent writing skills to assist with:

- ✔ *Collecting/organizing data*
- ✔ *Translating*
- ✔ *Producing and disseminating newsletter*
- ✔ *Writing proposals*
- ✔ *Networking activities*
- ✔ *Developing a web page*
- ✔ *Updating the database*

Position can be developed by the intern at home. Minimal time in the IID office in Rockville, MD is required (approximately 4-6 hours per week). Fluency in Spanish and/or Portuguese preferred.

For additional information, please contact: Rosangela Berman-Bieler, President, IID Headquarters, 711 Brent Road, Rockville, MD 20850, Telephone: (301) 838-3031, Fax: (301) 838-3029, E-mail: IIDisab@aol.com

National Efforts to Promote Conversion: Day Programs to Supported Employment

BY PAT ROGAN AND MARY HELD

Supported employment has enabled nearly 150,000 people in the United States to work successfully in the community. Yet, for every person in supported employment, there are approximately four people with disabilities in sheltered workshops, and the number is growing. Thousands more people remain congregated and segregated in non-work day activity (a.k.a. day wasting) programs, despite a growing body of research showing that quality of life outcomes are better for those living and working in integrated community settings.

Most organizations providing segregated day services have chosen to add supported employment to their continuum of services. A smaller number of organizations offer only community-based services. Fewer still have undertaken total changeover, or conversion, from facility-based to community-based services. However, demonstrations of total conversion are growing. In a recent national study of conversion (Rogan, Held, & Rinne, 1998), 12 organizations had totally converted, overcoming barriers often cited as reasons for maintaining the status quo, and 33 more were in the process of changeover. Positive outcomes were reported, with 91% indicating that people with disabilities were happier, 83% indicating services were better, 69% reporting better employer relations, and 64% reporting that staff were more satisfied. One of the most important outcomes of these conversion efforts is that, in the end, few (if any) people still preferred sheltered workshops. The converted agencies have demonstrated that segregated facilities are not needed for preparing people for the world of work. Why is our nation still directing most funding to support segregated day services? How can more segregated facilities be influenced to convert to community-based services? How can we offer integrated work opportunities to all citizens of our country? Such questions were the driving force behind two national forums on changeover to supported employment. The most recent forum is discussed below.

As a result of the February 1999 national forum on conversion, the following national priorities have been established:

- ***Strengthen the involvement of self-advocates in employment issues.***
- ***Develop a National Conversion Network to share information and push for reforms.***
- ***Influence policies and funding structures that act as disincentives to conversion.***
- ***Support organizations undertaking conversion through training and technical assistance.***
- ***Expand state level initiatives that support broad scale change.***

National Forum on Changeover to Supported Employment

In an effort to engage national and state leaders, providers, and advocates in discussions about conversion, a national forum was held in Phoenix, Arizona in February 1999. (A similar forum was held in Denver in 1997). Over 100 participants discussed successful strategies for overcoming barriers to conversion. Keynoters included Fred Schroeder, Commissioner of the Rehabilitation Services Administration, Sue Swenson, Commissioner of the Administration on Developmental Disabilities, and Liz Obermayer, Self-advocacy Specialist with the Massachusetts Department of MR and TASH Board member.

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National Efforts to Promote Conversion

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Research has demonstrated that people overwhelmingly express satisfaction with the preferences for their community job experiences. Organizations that have totally converted to integrated services have found that individuals with disabilities have no need for facility-based employment services. All services and supports can be provided successfully in an individualized fashion in the community at comparable costs to segregated services.

As a result of the forum, several national priorities have been established, including: developing a National Conversion Network to share information; expanding state-level initiatives that support broad scale change; and strengthening the involvement of self-advocates in employment issues.

National Organizations Support Integrated Employment Options

The Board of TASH has recently revised the association's resolution on integrated employment to reflect an emphasis on the need to provide equal access to integrated employment opportunities to people with the greatest support needs. Other highlights of the TASH Resolution on Integrated Employment include:

* Employment of people with significant disabilities must be in regular employment settings where they work along side people without disabilities. Frequent and ongoing interactions and the development of relationships must be insured.

* Employment must result in meaningful compensation for work performed, and include benefits comparable to co-workers without disabilities that perform similar work.

* Employment of persons with significant disabilities must be viewed as careers over time where job changes and advancement occur in the interest of higher pay, greater responsibility and variety, better working conditions and individual interest.

* The assistance and support provided persons with significant disabilities should be individualized according to needs and abilities, and should maximize natural supports provided by personnel in the workplace.

The Association for Persons in Supported Employment (APSE) has also developed a position statement as part of that organization's efforts to expand integrated employment and eliminate segregation. The position statement is entitled: *Toward Integrated Employment for All: APSE's Position on Segregated Services for People with Disabilities*, and was authored by Dale DiLeo and Pat Rogan. The statement discusses the crisis that has been reached in the unemployment and underemployment of people with high support needs who are considered to have the most significant disabilities. Supported employment, while not yet fully realizing its potential, offers by far the best opportunities for employment and a career for individuals most at risk of living life without a job. Yet, studies show the reality for most of these individuals is lifelong segregation in day treatment, habilitation, or sheltered training. Various national studies have shown:

- The majority of people with significant disabilities are in sheltered workshops (44%) and day activity programs 37%).

- Most employment service funding still supports segregated environments.

- A 1995 survey found that more people with disabilities entered segregated programs than supported and non-supported competitive employment combined.

Over the last ten years, supported employment has been studied extensively. We know how many people annually receive services, as well as their characteristics, wages, job types, costs, and other outcomes. We know that supported employment cost-benefit studies are positive, and that people significantly improve their wages, quality of life, and skill development when they access real jobs.

Research has demonstrated that people overwhelmingly express satisfaction with the preferences for their community job experiences. Organizations that have totally converted to integrated services have found that individuals with disabilities have no need for facility-based employment services. All services and supports can be provided successfully in an individualized fashion in the community at comparable costs to segregated services.

In contrast, there is very little national data about traditional, segregated day services in terms of wages earned, skills learned, movement to integrated employment, costs, and other quality of life measures. Yet the majority of funding, at both the federal and state levels, continues to support these traditional segregated programs.

While there are approximately 150,000 people working through supported employment, approximately 450,000 people remain in segregated, sheltered day programs.

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National Efforts to Promote Conversion

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Therefore, the Board of APSE has resolved that:

* No person should be denied the opportunity to have a real job in his or her community based on their disability or perceived support needs.

* The unacceptably high unemployment rate of people with disabilities must be addressed through community-based, integrated employment options. People need jobs and supports for job success, not segregation.

Why is our nation still directing most funding to support segregated day services?...Thousands of [people with disabilities] remain congregated and segregated in non-work day activity programs, despite a growing body of research showing that quality of life outcomes are better for those living and working in integrated community settings.

* Youth with disabilities transitioning to adult employment should move directly into integrated jobs, and should never be sent to workshops or segregated facilities to "get ready" for employment. Integrated employment and necessary supports must be available to all students at the time of school exit, regardless of intensity of support needs.

* "Successful vocational rehabilitation employment outcomes" must include only integrated, community-based employment, and appropriate experiences, supports, and opportunities must be available to support this outcome. Placement in segregated settings should never be considered a successful outcome.

For more information, or to become involved in conversion efforts, please contact Pat Rogan at (317) 274-6806, fax: (317) 274-6864, e-mail: PROGAN@IUPUI.EDU.

Reference

Rogan, P., Held, M., & Rinne, S. (1998). A national study of conversion from facility-based to community-based employment services. Indiana University: Institute for the Study of Developmental Disabilities.

TASH wishes to acknowledge the generous support of our newest Lifetime Members

Michael Auberger
Dianne Ferguson
Elisabeth Healey

Lifetime membership entitles you to full international and chapter member benefits for your lifetime. The cost can be remitted over several monthly payments. If you are interested in becoming a lifetime member of TASH, contact Rose Holsey at 410-828-8274, ext. 100.

ARE YOU A UNIVERSITY PROFESSOR?

TASH has a Student Membership Program!

The program was developed through discussions with professors who wanted to encourage professional identity through student membership in a strong advocacy organization while assuring that their students had access to enough issues of JASH for them to be able to complete a variety of journal article review and comparison exercises they assign.

The package works like this:

Professors can either assign TASH membership as one would a text book or package of readings, or can offer it as an option. Either way, if ten or more students join, they receive a discount off the already low student rate. The discount amount increases as the number of students signing up increases.

Regardless of how many students join, TASH provides a year's worth of back issues of the journal to all students signing up under this plan. This means your students will start the semester with a year's worth of cutting edge research on their shelf and can build their collection over the years to come. Under this plan, students receive all of the regular membership benefits during the coming year-in addition to an extra full year's worth of journals.

An introduction to TASH is likely to be one of the most valued resources you can offer students as they enter the disability community in their professional capacities. To receive materials or to learn more about TASH's student membership program, contact Rose Holsey, 410-828-8274, ext. 100 or e-mail: rholsey@tash.org

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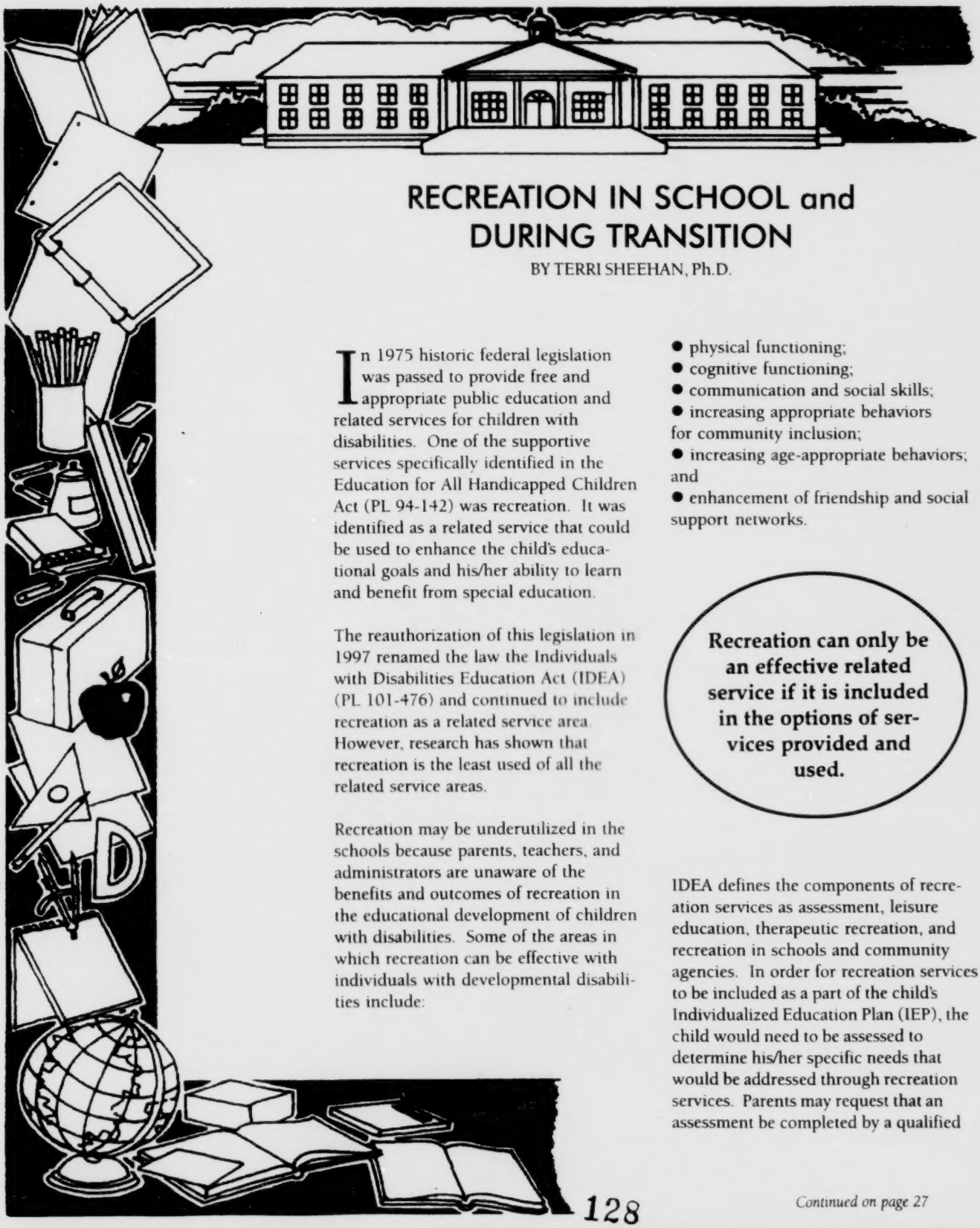

RECREATION IN SCHOOL and DURING TRANSITION

BY TERRI SHEEHAN, Ph.D.

In 1975 historic federal legislation was passed to provide free and appropriate public education and related services for children with disabilities. One of the supportive services specifically identified in the Education for All Handicapped Children Act (PL 94-142) was recreation. It was identified as a related service that could be used to enhance the child's educational goals and his/her ability to learn and benefit from special education.

The reauthorization of this legislation in 1997 renamed the law the Individuals with Disabilities Education Act (IDEA) (PL 101-476) and continued to include recreation as a related service area. However, research has shown that recreation is the least used of all the related service areas.

Recreation may be underutilized in the schools because parents, teachers, and administrators are unaware of the benefits and outcomes of recreation in the educational development of children with disabilities. Some of the areas in which recreation can be effective with individuals with developmental disabilities include:

- physical functioning;
- cognitive functioning;
- communication and social skills;
- increasing appropriate behaviors for community inclusion;
- increasing age-appropriate behaviors; and
- enhancement of friendship and social support networks.

Recreation can only be an effective related service if it is included in the options of services provided and used.

IDEA defines the components of recreation services as assessment, leisure education, therapeutic recreation, and recreation in schools and community agencies. In order for recreation services to be included as a part of the child's Individualized Education Plan (IEP), the child would need to be assessed to determine his/her specific needs that would be addressed through recreation services. Parents may request that an assessment be completed by a qualified

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Recreation in School and During Transition

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recreation professional, such as a Certified Therapeutic Recreation Specialist (CTRS) to determine if the child would benefit from recreation services to enhance the learning experience.

Leisure Education Programs

Based on the needs identified through assessment, a classroom-based leisure education program may be added to the child's special education program. Leisure education programs could be used to develop:

Social skills such as

- cooperation
- assertiveness
- conversation skills
- appropriate social interactions

Recreation skills such as

- sports
- music
- volunteering
- nature and outdoor activities

Participatory skills such as

- decision-making
- follow through on choices
- self-initiation
- self-motivation

The development of these skills will enable the child to participate in appropriate opportunities.

Therapeutic Recreation Programs

The second component that could be added is therapeutic recreation. Therapeutic recreation would be provided on a one-to-one basis or in small groups in order to achieve specific behavioral outcomes. These outcomes may include improving functional and adaptive abilities such as concentration, listening, following instructions, understanding rules and procedures, perceptual motor skills, balance, agility and endurance. These interventions and treatments would focus on assisting the development of functional skills necessary for participation in leisure pursuits independently in the community.

Recreation During Transition

The last component identified in the IDEA is recreation in the schools and community agencies. This area, as well as leisure education, will become more important during the mandated transition program which should begin at age 13, but in some cases as late as age 16.

The transition program from school to adult life should be based on the student's interests and preferences with respect to vocational training, leisure, community participation and independent living. Recreation services in the school would be used to promote participation in extra-curricular activities as part of the transition to post-school life. Recreation in community agencies would be used to develop independent functioning skills, identification of resources in the community and opportunities for inclusive participation.

Recreation may be more effective than other related services due to the experiential nature of the service. However, in order for recreation to be effective, it needs to be included in the options of services provided and used.

Terry Sheehan works at St. Cloud State University in Minnesota.

Additional information on the IDEA is available at the federal government web site http://www.ed.gov through the Office of Special Education.

Information on recreation in the schools can be obtained through Project TRAIN at the University of Wisconsin at La Crosse web site http://www.uwlax.edu/HPER/RM-TR/

TEACHERS: Children with Significant Disabilities

Public schools on beautiful Oregon coast have immediate openings for innovative, collaborative teachers with licensure and education/experience with students with significant disabilities.

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(541) 269-4520

The National Supported Employment Consortium for the Competitive Employment of People with Significant Disabilities

BY GRANT REVELL

The National Supported Employment Consortium (SEC) for the competitive employment of people with significant disabilities is designed to critically evaluate the effectiveness to date of supported employment and to provide training and technical assistance on exemplary programs and practices for the purpose of improving and expanding its impact. The SEC was funded effective October 1, 1997 by the Rehabilitation Services Administration for three years with a possibility of extension for an additional two years. The SEC project is administered by the Virginia Commonwealth University Rehabilitation Research and Training Center (VCU RRTC), and consortium members include the Indiana Institute on Disability and Community, the Boston Children's Hospital Institute for Community Inclusion, Transcen, Inc., and the University of Montana Rural Institute on Disabilities. Paul Wehman at the VCU RRTC is the principal investigator.

The SEC is designed to address the following question: At the state, community, and individual participant level, what are the most effective practices and programs that improve the competitive employment opportunities and supports available to people with significant disabilities? It has been more than 10 years since supported employment was added as a recognized rehabilitation outcome through the Rehabilitation Act Amendments of 1986, and the impact of supported employment still varies greatly. For every instance of persons with the most significant disabilities working with ongoing supports in career-oriented positions that reflect personal choice and pay well above minimum wage along with benefits, others in supported employment are working on the fringes of the competitive labor market with marginal wages. The use of supported employment appears to have little impact to date on the consistently high unemployment rate of persons with a significant disability who say they want to work. Growth is still occurring in the use of segregated settings even as the service technology on how to support individuals across the full range of disabilities in the community continues to improve. Funding possibilities such as the Home and Community Based (HCB) Medicaid Waiver program remain underutilized for supported employment services in most states, and the challenge remains of how to merge natural and other supports into effective and real individualized ongoing support plans.

The SEC is conducting studies in ten areas to identify the best practices and develop new strategies that address the challenges facing supported employment. The evaluation study areas are: statewide systems change, cost benefit analysis, extended services, employer impact, meaningful employment outcomes, consumer self-determination and the use of personal assistance services, natural supports, analysis of federal and state policies, use of interagency agreements, and persons unserved or underserved in supported employment. The SEC will widely disseminate information gained from these evaluation studies and from other efforts to identify best practices.

During 1999, the SEC is sponsoring monthly practioner focused day-long training programs on areas such as successful job restructuring strategies, strategies for providing supports in the workplace, and approaches to disability specific supports for persons with a physical disability, mental illness or brain injury. These trainings are being conducted all around the country. More information can be obtained on them by contacting wstrobel@saturn.vcu.edu or by calling (804) 828-1851. A business partnership training series is being conducted by Transcen, Inc (mleedy@transcen.org or call (301) 424-2002).

A week long supported employment summer institute will be held in Richmond, Virginia the week of August 9-14, 1999 to provide intensive instruction on supported employment best practices (kinge@atlas.vcu.edu). All of the consortium members are involved in a variety of technical assistance activities. More information can be obtained on the SEC evaluation studies and training and technical assistance activities through its web site at http://www.vcu.edu/rrtcweb/sec or by contacting Grant Revell, SEC Project Manager, at wgrevell@saturn.vcu.edu (email), 804 828-1851 (voice), 804 828-2193 (fax), or 804 828-2494 (TDY).

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All Kids Seek Ordinary Goals

BY EMILY JONES(Age 14)

I think it's disturbing that Evergreen School District (located in Vancouver, Washington) is going back to self-contained classrooms, as reported in the "Special Ed Plan Assailed" article that ran in the Columbian newspaper on April 1st . After finally winning the battle to get kids with disabilities in regular classrooms, we are going to go back to square one. I thought we already decided that being around peers and positive role models was most effective. Now we are reversing what we know is best and what we've seen work so we can bring back what we already had -- nothing. I believe that we have made a lot of progress in special needs education and we should not let ourselves regress into what we already came from.

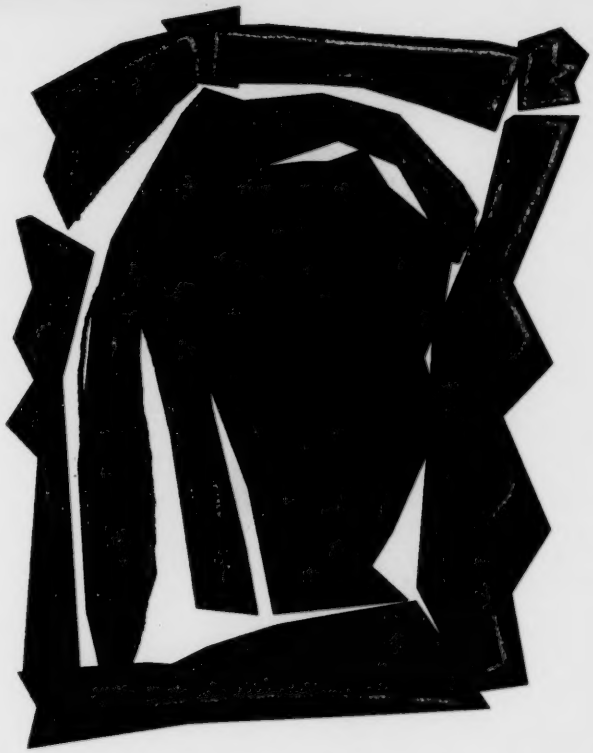
I have a sister who is three years old and has Down syndrome. She, along with most children, need to be in a setting where they are with peers and I don't mean other people with Down syndrome. I think of her no differently than the rest of my siblings; they all need to have a learning environment with positive modeling behavior. If they are in a class with all children with disabilities, it would be only natural for them to copy off each other -- one unwanted behavior turns into a whole room full of misbehaving children. However, if what they are around is quiet, attentive children, this is the behavior they will model.

If we start separating them in school, it will only continue into the rest of their lives. I know my parents want me to grow up, get a job, and live on my own. I think this is every parent's goal for their children. Why should the goals be different for children with disabilities?

I thought the goal was to have kids with disabilities progress into as "normal" a life as possible. Don't people realize that by going back to self-contained classrooms, we are giving up our dreams?

Abby (left, 3 1/2) and Emily (right, 14) Jones reside with their parents and their three other siblings in Vancouver, Washington. The above article contains excerpts from an op-ed piece written by Emily that appeared in the April 14th Columbian, a newspaper in Vancouver, Washington.

Institute on Abuse & Neglect of Persons with Disabilities



" Most people with disabilities will experience significant abuse, violence, or neglect sometime in their lives and people with disabilities are more than twice as likely to experience crimes of violence as people without disabilities."

- Dick Sobsey

This Institute is designed to bring together internationally known experts in the field of abuse, neglect, and victimization of individuals with developmental disabilities with researchers, practitioners, policymakers, and consumers to discuss the latest in research and best practices. For three days, on the beautiful New Hampshire seacoast, learn about important information related to the victimization of individuals with disabilities, and policy and practice, initiatives to create safe and secure communities for all.

Featured Speakers:

Dick Sobsey, Ph.D ■ David Finkelhor, Ph.D ■ Patricia Sullivan, Ph.D ■ Ruth Ryan, MD. ■ Deb Jones ■ John Knutson, Ph.D ■ Tanis Doe, Ph.D

For registration information contact Deb at The Institute on Disability/UAP 603.228.2084 or visit us on the web at http://iod.unh.edu

[illegible] UNH Institute on Disability/UAP and the UNH Center for Child Welfare • NH Division of Children Youth and Families • NH Division of Developmental Disability Services

1999 Calendar of TASH Chapter and Member-Sponsored Conferences

JULY

Project CHOICES Summer Institute: "Kids: Our Future"
July 22 and 22
Crowne Plaza Hotel, Springfield, Illinois
Contact: Project CHOICES
Phone: 630-778-4508
E-mail: ECHOICES@aol.com

CAL-TASH Summer Symposiums in Santa Barbara
July 26-27 - "School Inclusion"
July 29-30 - "Positive Behavior Support"
Contact: Eileen Medina
Phone: 805-967-2042
E-mail: cal-tash@ceo.sbceo.k12.ca.us

SEPTEMBER

National Spinal Cord Injury Association
Annual Meeting and Education Conference
September 26-29
Washington, D.C. Marriott at Metro Center
Contact: Denise Marshall
Phone: 410-828-8274, ext. 103

OCTOBER

8th Annual St. Amant Centre Conference "20th Century Trends, 21st Century Services?"
October 7 and 8
CanadInn, Winnipeg, Manitoba
Contact: Colette Choquette
Phone: 204-256-4301, ext. 298

DECEMBER

Annual TASH International Conference
"TASH 2000 - Our Turn Now"
December 8-11
Chicago Hilton and Towers
Contact: Kelly Nelson
Phone: 410-828-8274, ext. 105 or 1-800-482-8274, ext. 105
E-mail: knelson@tash.org

Do you have an upcoming TASH chapter meeting or member-sponsored conference that you would like to announce in the Newsletter? Send notice of the conference to Denise Marshall at dmarsh@tash.org at least 6 weeks before the event date. We will make every effort to include the event in the meetings calendar.

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TASH NEWSLETTER

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

Priscilla Newton, *Editor*

Executive Board

Liz Healey, *President*
Doug Biklen, *Vice President*
Donna Gilles, *Chair of the Executive Committee*
Liz Obermayer, *Secretary*
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Is the above your ❑ work address ❑ home address ❑ other_____

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( ) Administrator/Other
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Moving? ***Please notify TASH of your new address.***

General Membership (individual) $88
Agency/business/university/college/library/school $200
(allows 3 conference attendees at the member rate)
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Family (group rate) $136
Lifetime Member $1000
Add $10 for postage costs for members in Canada and $25 for members outside the U.S. and Canada.

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Student I.D. Number_____

Anticipated year of completion_____

( ) Include an additional $15 if you are applying for an individual membership or $30 if you are applying for an organizational membership and also want to become a member of your local chapter.

Please make check payable to: TASH
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29 West Susquehanna Avenue
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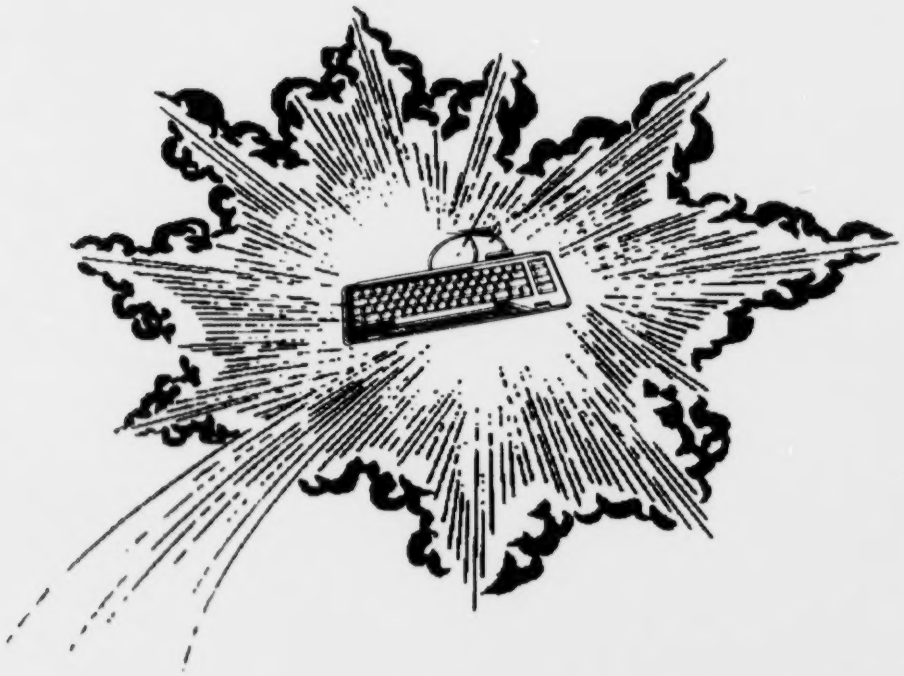
TASH

Newsletter

VOLUME 25 ISSUE NUMBER 3 July/AUG ~~MARCH~~ 1999

The Right to Communicate



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URGENT! Dated Material Inside!
TASH Board Election Ballot

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

~

Building communities in which no one is segregated and everyone belongs;

~

Forging new alliances that embrace diversity;

~

Advocating for opportunities and rights;

~

Eradicating injustices and inequities;

~

Supporting research and disseminating knowledge and information;

~

Promoting inclusive education;

~

Supporting progressive legislation and litigation; and,

~

Promoting excellence in services.

From the Executive Director
BY NANCY WEISS

Highlights of Summer '99 Board Meeting

The TASH Executive Board met for two agenda-packed days in Chicago in mid-July. Highlights of the meeting are as follows:

Strategic Plan: The Board reviewed progress on TASH's 1999 Action Priorities. Progress had been made on all ten action plans. TASH's Advocacy-Related Priorities for 1999 include:

- IDEA Enforcement
- Communication Rights
- Passage of MiCASSA
- Collaboration with General Educators
- Criminal Justice Related Issues

TASH's Operations-Related Priorities include:

- Improve our Web Site and Electronic Communication
- Synthesize Resolutions and Develop New Resolutions
- Better Communication with Chapters
- Develop a Handbook for Students on Their Rights Under IDEA
- Fiscal Development

Financial Report: TASH's fiscal health continues to improve. The 1998 Financial Statements were reviewed. 1998 revenues increased almost 30% over Fiscal Year 1997, and have increased by more than 265% over the past five years. Assets more than doubled from 1997 to 1998 as well, putting TASH in a relatively

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Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about the 1999 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on governmental affairs, call:** Dan Dotson, Acting Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:ddotson@tash.org
- **For information on marketing and promotions, permission and reprints, newsletter submissions and advertising, or publication sales, call:** Priscilla Newton, Director of Marketing and Communications, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the Journal (JASH), call:** Linda Bambara, Editor-in-Chief, at (610) 758-3271, e-mail: LMB1@lehigh.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette, in large print, and in Braille for people whose disabilities make these alternative formats preferable. Call (410) 828-8274 ext. 102 to request an alternative format. Requests for permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org.

Highlights of Summer '99 Board Meeting

Continued from page 2

strong financial position for the coming years.

Development Efforts: Joe Wykowski, Chair of the Finance Committee is working on a number of development-focused initiatives including corporate relationships and a planned giving campaign.

Information and Referral System: Denise Marshall of the TASH staff is working on a triage system and computerized data base for responding to requests for information and referral. The Board suggested we look into employing a VISTA worker to enter information and handle general information requests.

Publications Catalogue: Denise is finalizing plans for the Publications Catalogue. The purpose of the catalogue is to disseminate the work of TASH members. We will likely contract with an existing company to produce the TASH Book Store on-line, publish the catalogue and receive and fill orders.

TASH Annual Conference Update: Kelly Nelson reported that proposals are in and the review process is almost completed. Presenters will be notified of their acceptance in August. A number of exciting events are being planned in conjunction with the conference, including a beach party reception as a kick-off for next year's conference in Miami and a TASH 25th Anniversary CD.

Conference Yearbook: 1999 will be the inauguration of the TASH Yearbook. The Yearbook will be a compendium of selected manuscripts describing many of the conference presentations. The Yearbook will be available for pre-sale at a reduced rate in conjunction with conference registration. The idea for the yearbook was suggested by Doug Fisher, Chair of the Education Committee. He and Craig Kennedy will serve as Editors.

Conference Marketing: Priscilla Newton described efforts to secure sponsorships and related support for the annual conference. Last year the following companies participated: Black & Decker, Columbia Winery, Microsoft, Pepsi Cola, the Seattle Seahawks, Southwest Airlines, and William M. Mercer Co. This year we are offering sponsors three levels at which they can participate, ranging from $2,000 to $7,500. We are also working with the Chicago Mayor's Office for People with Disabilities to secure in-kind services to help promote the conference. It is likely that the Mayor's Office for People with Disabilities will be a major sponsor of this year's conference.

Updates on Other TASH-Organized Conferences: In addition to TASH's annual conference, staff are working on three other events. TASH is organizing the annual conference of the National Spinal Cord Injury Association. It will be held September 26 - 29, 1999 in Washington, D.C. We are also planning a two-day workshop with the Center for Human Policy for the Spring. The topic will be "Organizing for Disability Rights and Inclusion." Finally, along with an international planning committee, we are organizing the International Conference on Self-Determination and Individualized Funding for Seattle, July 29-31, 2000.

Revision of Bylaws: We have had an attorney review our bylaws and make recommendations for revisions. The Board is considering the pros and cons of re-incorporating in Maryland. This decision must precede final revisions to the bylaws as they need to conform to the laws of the state in which the organization is incorporated. Once the bylaws are revised, a vote of the membership will be taken by sending ballots out with renewal notices.

Discussion of Name Change: The Board again discussed concerns about TASH's name. A sub-committee volunteered to discuss name change options and make a recommendation to the Board and membership.

A New Name for the *Newsletter*: It is widely agreed that the title "The *Newsletter*" doesn't do justice to this publication. The *Newsletter* is not a newsletter (with updates about who received grants and promotions) but much more like a small magazine. Various options were discussed. It was agreed that the Board, Committee Chairs and Chapter officers would be surveyed by e-mail with the final possible names published in the *Newsletter* for member input.

Membership Committee Report: Liz Obermayer presented the Membership Committee report. The results of a membership survey were reviewed. Several changes to membership categories were discussed. It was agreed that we would eliminate the reduced-fee membership categories (for students, self-advocates and parents) and substitute an associate member category available to anyone with a household income of $25,000 or less annually. We are also eliminating the "organizational representatives" feature of organizational memberships, instead offering discounts to three or more individuals joining from the same organization. The group-family rate is being eliminated as well, and it was agreed that the price of a lifetime membership would be increased to $1,300 on January 1st of 2001.

Governmental Affairs: Marcie Roth and Mike Auberger reported on TASH's governmental affairs work. The Board discussed the legislative agenda for TASH and strategies for accomplishing legislative and public policy changes in light of Marcie Roth's departure (see page 15). It was agreed that the implementation and enforcement of IDEA, along with passage of MiCASSA should continue to be the major focal points of governmental affairs work.

Committee Issues: Several changes in Board assignments were made. Patrick Schwarz will serve as Board Liaison to the Elections Committee. Jacki Anderson will serve as Liaison to the Publications Committee. Liz Obermayer will

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America's People with Disabilities -- Seniors, Adults and Children with Disabilities -- Need the Medicaid Community Attendant Services and Supports Act (MiCASSA) in 1999

Our thanks to National ADAPT for supplying the information contained in this article.

Inadequacy of Long-Term Service Delivery System

For decades people with disabilities, both old and young, have wanted alternatives to nursing homes and other institutions when they need long-term services. Our long-term care system has a heavy institutional bias. Every state that receives Medicaid must provide nursing home services, but community-based services are optional. Over eighty percent of Medicaid long-term care dollars ($41 billion) pay for institutional services, while the remaining 20% must cover all the community-based waivers and optional programs.

America's long term-service system must change. Created over thirty years ago, it is funded mainly by Medicare and Medicaid dollars. These are medical dollars which were not originally conceived to meet the long-term care needs of people. A national long-term service policy should not favor any one setting over the other. It should be neutral and allow the users to choose where services should be delivered. The current system is not neutral.

Community services on average have been shown to be less expensive — and more desired by individuals — than institutional services. Nursing home care costs taxpayers more than it costs to support people in their own homes, even when these people are receiving other public benefits. People with disabilities, both old and young, including those with significant mental and/or physical disabilities, want services in the most integrated setting possible. People with disabilities and their families want REAL choice, which means:

- equitable funding opportunities;
- no programmatic or rule disincentives to community services;
- options for services delivery to include agencies, vouchers and fiscal intermediaries.

Medicaid Community Attendant Services and Supports Act of 1999

HR 2020, the Medicaid Community Attendant Services Act, MiCASA, was introduced on June 24th, 1997 by Speaker of the House Newt Gingrich, and gained bipartisan support and a hearing in the House Commerce Committee. When the legislative session ended, this version of MiCASA died. However, the bill has since been rewritten with input from groups from the aging, developmental disability, independent living and other groups interested in long-term services and supports. This new version is called MiCASSA (Medicaid Community Attendant Services and Supports Act).

MiCASSA gives people real choice in long-term services. Amending Title XIX of the Social Security Act (Medicaid), MiCASSA creates an alternative service called Community Attendant Services and Supports. It allows individuals eligible for Nursing Facility Services or Intermediate Care Facility Services for the Mentally Retarded (ICF/MR) the choice to use these dollars for "Community Attendant Services and Supports." The dollars would follow the individual, rather than being committed to the facility or the provider.

Specifically, MiCASSA will:

- Provide community attendant services and supports which range from assisting with activities of daily living (eating, toileting, grooming, dressing, bathing, transferring), instrumental activities of daily living (meal planning and preparation, managing finances, shopping, household chores, phoning, participating in the community), and health-related functions.

- Include hands-on assistance, supervision and/or cueing, as well as help people to learn, keep and enhance skills to accomplish such activities.

- Require services to be provided in the most integrated setting appropriate to the needs of the individual.

- Provide Community Attendant Services and Supports that are:

  - based on an assessment of functional need;
  - provided in home or community settings such as school, work, recreation, or religious setting;

MiCASSA's goal is to provide flexible, consumer-responsive services, which means that the person receiving the services decides how, when and where they are provided. In short, MiCASSA will allow for consumer control.

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America's People with Disabilities Need MiCASSA in 1999

Continued from page 4

- selected, managed and controlled by the consumer of the services;
- supplemented with backup and emergency attendant services;
- furnished according to a service plan agreed to by the consumer and including voluntary training on selecting, managing and dismissing attendants.

●Allow consumers to choose among various service delivery models, including vouchers, direct cash payments, fiscal agents and agency providers, all of which are required to be consumer controlled.

●Allow for an "individual's representative" to be authorized by the consumer to provide assistance in instances where the consumer is not able to direct his/her own care independently. A representative can be a friend, family member, guardian, or advocate.

●Allow health-related functions or tasks to be assigned to, delegated to, or performed by unlicensed personal attendants, according to state laws.

●Cover individuals' transition costs from a nursing facility or ICF/MR to a home setting. Examples of such costs include rent and utility deposits, bedding, basic kitchen supplies and other necessities required for the transition.

●Serve individuals with incomes above the current institutional income limitation, if a state chooses to waive this limitation to enhance the potential for employment.

●Provide for quality assurance programs which promote consumer control and satisfaction.

●Allow states to limit the aggregate amount spent on long-term care in a year to that amount the state would have spent for a year of institutional services for such eligible individuals.

●Provide a maintenance of effort requirement so that states can not diminish more enriched programs already being provided.

MiCASSA also provides grants for Real Choice Systems Change Initiatives to help the states transition from the current, institutionally-dominated service systems to systems more focused on community services and supports. Each state will create a Consumer Task Force to develop a plan for transitioning services into a more community-oriented system. A majority of the members must be people with disabilities or their representatives. The Secretary of Health and Human Services, along with the National Council on Disability, will review regulations and report to Congress on how to reduce excessive use of medical services. The Secretary will also establish a task force to examine financing of long-term care services.

SUPPORT MiCASSA NOW!

Frequently Asked Questions About MiCASSA

We've attempted to provide answers to some of the most frequently asked questions about eligibility and coverage criteria under MiCASSA and how the program will operate.

1. How are community attendant services and supports defined in MiCASSA?
In MiCASSA, the term community attendant services and supports means help with accomplishing activities of daily living (eating, toileting, grooming, dressing, bathing, and transferring) instrumental activities of daily living (meal preparation, managing finances, shopping, household chores, phoning, and participating in the community), and health-related functions which can be delegated or assigned as allowed by state law). These can be done through hands-on assistance, supervision and/or cueing. The term also includes help with learning, keeping and enhancing skills to accomplish such activities.

These services and supports, which include back-up, are designed and delivered under a plan that is based on a functional needs assessment and agreed to by the individual or family, in the case of a child. In addition they are furnished by attendants who are selected, managed, and dismissed by the individual or family, and include voluntary training for the individual or family on supervising attendants.

MiCASSA specifically states that services should be delivered, "in the most integrated setting appropriate to the needs of the individual" in a home or community setting, which may include a school, workplace, recreation or religious setting.

2. If someone can't manage their attendant services completely independently, is he/she still eligible for MiCASSA services?
Yes. People who have difficulty managing their services themselves due to a cognitive disability, for example, can have assistance from a representative, like a parent, a family member, a guardian, an advocate, or other authorized person.

3. Do you have to be impoverished to be eligible for MiCASSA?
No. If you are eligible to go into a nursing home or an ICF/MR facility, you would be eligible for MiCASSA. Financial eligibility for nursing homes is up to 300% of the SSI level. In addition, states can choose to have a sliding fee scale for people of higher incomes. MiCASSA specifically references this as an incentive for employment. This sliding fee scale can go beyond the current Medicaid eligibility guidelines.

4. Is MiCASSA biased towards an agency delivery model?
No. MiCASSA assumes that "one size does not fit all." It allows the maximum

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America's People with Disabilities Need MiCASSA in 1999

Continued from page 5

amount of control preferred by the individual with the disability. Options include: vouchers, direct cash payments or a fiscal agent, in addition to agency delivered services. In all these delivery models the individual (or a child's family) has the ability to select, manage and control attendant services and supports, as well as help develop a service plan. Choice and control are key concepts, regardless of who serves as the employer of record.

5. Will MiCASSA replace existing community-based programs?
MiCASSA does not affect existing optional programs or waivers and includes a maintenance of effort clause to ensure these programs are not diminished. Waivers include a more enriched package of services for those individuals who need more services. With MiCASSA, people who are eligible for nursing homes and ICF/MR facilities can choose community attendant services and supports as a unique service that is a cost-effective and high-quality option. The money follows the individual rather than being directed to a facility.

6. Is MiCASSA a new unfunded mandate?
No. MiCASSA is a way to make an existing mandate for nursing homes and institutions for people with mental retardation responsive to the needs and desires of the consumers of these services. MiCASSA says the people who are already eligible for these services will simply have a choice regarding where they receive services. MiCASSA would adjust the current system to focus on the recipients of service, instead of mandating funding for certain industries and facilities.

7. Will MiCASSA be expensive? What about the "woodwork" effect?
MiCASSA assures that a state need spend no more money in total for a fiscal year than would have been spent for people with disabilities who are eligible for institutional services and supports.

There is a lot of discussion about the people who are eligible for institutional services; that there are people who would never go into an institution, but would jump at the chance to use MiCASSA. (This is called the woodwork effect, as in "coming out of the woodwork.") The states of Oregon and Kansas have data to show that fear of the woodwork effect is greatly exaggerated. There may be some increase in the number of people who use the services and supports at first, but savings will be realized by using the less costly community-based services and supports, as well as through the decrease in the number of people going into institutions.

Belief in the woodwork effect assumes a lot of "free care" is now being delivered by caregivers. There is a real question whether this care is truly "free." Research on the loss to the economy of the "free" caregivers is just being initiated.

8. What are the transitional services?
Currently, Medicaid does not cover some essential costs for people coming out of nursing homes and ICF/MR facilities. These include deposits for rent and utilities, bedding, kitchen supplies and other things necessary to make the transition into the community. Covering these costs would be one of the services and supports covered by MiCASSA.

9. How is Quality Assurance addressed in MiCASSA?
States are required to develop quality assurance programs that set down guidelines for operating Community Attendant Services and Supports, and provide grievance and appeals procedures for consumers, as well as procedures for reporting abuse and neglect. These programs must maximize consumer independence and direction of services, and measure consumer satisfaction through surveys and consumer monitoring. States must make public the results of the quality assurance program, as well as an on-going process of review. Sanctions must be developed and the Secretary of Health and Human Services must conduct quality reviews.

10. What is the purpose of the Real Choice Systems Change Initiatives section of the bill?
MiCASSA brings together on a consumer task force the major stakeholders in the fight for community-based attendant services and supports. Representatives from developmental disabilities councils, independent living councils and councils on aging, along with consumers and service providers would develop a plan to transition the current institutionally biased system into one that focuses on community-based attendant services. Closing institutions, or even reducing bed spaces, must be thought through by the people that have an investment in the final outcome — the consumers. The plan envisions ending the fragmentation that currently exists in our long-term service system.

In addition, the bill sets up a framework and funding to help the states transition from their current institutionally dominated service model to more community-based services and supports. States will be able to apply for systems change grants for activities like: assessing needs and gathering data, identifying ways to modify the institutional bias and over medicalization of services and supports, coordinating between agencies, training and technical assistance, increasing public awareness of options, downsizing of large institutions, paying for transitional costs, covering consumer task force costs, demonstrating new approaches, and other activities which address related long-term care issues.

MiCASSA Helps Families of Children with Disabilities

The vast majority of families don't want to place children with disabilities in

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America's People with Disabilities Need MiCASSA in 1999

Continued from page 6

institutions. Families want children to live at home where they can maintain family ties, go to school and grow as other children do. Families also want their children to have a secure future and real options for home and community services and supports when their families are no longer providing full-time care.

Young people with disabilities are not in institutions or foster care because of the amount of care they need. They are in these settings because of the lack of attendant services and supports. Many children with significant disabilities do, in fact, live at home with their families. Some of the real reasons why children and young adults with disabilities go into institutions or nursing homes are:

•Parents can't hold down a job that supports their family and provide full-time care to a child with disability;

•Parents may be able to provide much of the care that a young child needs, but may not be physically able to manage lifting and positioning as the child grows;

•Parents fear that when their child is old enough to move out of the house, no independent living, community options will be available;

•Public policy supports institutions, not people with disabilities and their families; and

•Family members may not know that there are alternatives to nursing homes and other institutions for their children with disabilities.

MiCASSA provides Medicaid funding for attendant services and supports for people of all ages. Services can be provided at home, in school, at work and at play. Assistance is available for a broad range of needs, such as bathing, dressing, meal preparation, money management and certain health-related tasks. And MiCASSA will be available to young adults when they move out of their parents' homes into the community.

MiCASSA Means REAL Choice

The demographics of our nation are changing. The population is aging, and breakthroughs in medical technology are increasing the life expectancy for all people — including people with disabilities. Most Americans who need long-term services and supports would rather remain in their own homes and communities than be forced to move to a nursing home or other institution. MiCASSA redirects the focus of the Medicaid long-term services program from institutions to home and community services and supports. It enables people to make real choices.

Studies show that people currently living in America's institutions and nursing homes do not have more significant disabilities than people who are living in their own homes with attendant services and supports. So why do they go into institutions when they would rather live in the community in their own homes? Because:

❖Family members and other informal caregivers "burn out" or "age out";
❖Government does not provide a real choice for home and community-based services;
❖Home care pays caregivers low wages and generally offer no benefits, which results in a shortage of qualified providers;
❖People don't know that there are alternatives to nursing homes and other institutions.

The needs of people who use community attendant services and supports are understood best by people with disabilities. MiCASSA would give people with disabilities a policy-making role in designing America's community attendant services and supports program and deciding what services will be available, how they are paid for, and who is eligible. Many people with disabilities can and want to select, train, and supervise their own attendants. For them, MiCASSA provides options such as vouchers with which to pay attendants (including family members) and training in directing and managing their care. For those who prefer not to manage their own services, it also provides for a consumer-directed agency model.

MiCASSA's goal is to provide flexible, consumer-responsive services, which means that the person receiving the services decides how, when and where they are provided. In short, MiCASSA will allow for consumer control.

How Can You Help Support Passage of MiCASSA?

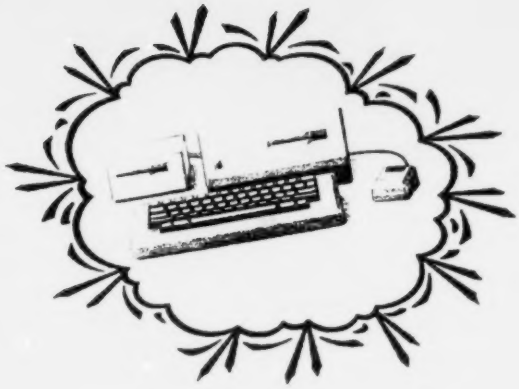
Keeping people in the community allows the possibility for individuals with disabilities to train for work so they can become taxpayers rather than tax users. The Federal government needs to work in partnership with the states to create flexible delivery systems that give people real choice.

When your senators and congressional representatives are back at home in your state for weekends or during their breaks, plan a visit and update him/her about the bill and why it is important that he/she support it. We need Congressional representatives to sign onto MiCASSA as co-sponsors.

The elected national representatives in your district need to hear from you. Without constituents on a grassroots level contacting their representatives, MiCASSA will not garner the support it needs for passage.

DON'T KNOW WHO YOUR CONGRESSPERSON IS?

Contact the Congressional Switchboard at 1-800-962-3524, or call your local Democratic or Republican party headquarters (listed in the local telephone directory). Don't forget to ask for the local address and phone number for your representatives. You can also e-mail your representatives right through the TASH web site. Visit the site at www.tash.org, click on "Governmental Affairs," then "Government Affairs Links," then "U.S. Senate" or "U.S. House of Representatives."



Talking Politics: EMPOWERING COMMUNICATION AID USERS

BY ROSEMARY CROSSLEY

Recently I had a phone call which reminded me how important communication is, and how vulnerable it is for people who cannot use their own voices.

The caller was 'Laura," mother of "Fred," an adult with multiple disabilites who had used a Canon Communicator (a miniature typewriter) at his day center and at home for many years. Because of his disabilities, it is essential that someone holds the communicator and supports Fred's arm while he types. Last year, Fred moved to another day center, which apparently doesn't believe in using any communication aids, and his attendant carers changed. This left his elderly mother as his only communication partner, and she only got out Fred's Canon when she wanted to know something, not when he had something to say.

Laura called me to say that she had just discovered that Fred is blind in one eye, due to a detached retina caused by him hitting himself when he was frustrated. She feels very guilty about this, and feels that his reduced communication opportunities have contributed to his frustration. Laura has been trying to get Fred a Macaw (a communication device on which words and sentences are recorded by a speaking person) for some time, which would be easier for him to use without facilitation. While he was waiting for this, his communication seems to have fallen into a black hole, with no new partners being trained.

While a number of factors contributed to this tragedy, it seems reasonable to suggest that if everyone in Fred's life had recognized that he had a right to communicate, it may have been prevented. The day center would have enabled him to use his Communicator. The attendants would have been trained. Back up would have been provided for Laura as she aged, or a more independent communication strategy could have been found for Fred. The agency responsible for providing the new aid would have done so more quickly. And so on. As it was, communication was apparently seen as an optional extra for Fred, to be provided or not at the whim of others. Silencing Fred was easy, because without his Communicator, he had no way of complaining.

DISEMPOWERMENT

A journey of a thousand miles starts with one step. The first step in establishing a right to communicate for people without speech is to examine the current situation. An over-riding theme in the accounts of communication aid users is the disempowerment which many people with communication disabilities, regardless of diagnosis or age, have experienced — often at the hands (or on the recommendations) of professionals, but also in their families and the community at large. Disempowerment is often associated with an absence of communication, either because a means of communication has not been provided, or because an individual's communication strategy is for some reason unacceptable.

An associated issue is the relative importance given to the convenience of people without disabilities and the convenience of people with communication disabilities. While this obviously affects people who use facilitated communication, it also affects everybody whose communication is partner-dependent. The issue of convenience arises often with communication boards, which are inconvenient for the person receiving the communication because

Every person, regardless of the severity of his/her disabilities, has the right and the ability to communicate with others, express everyday preferences and exercise at least some control over his or her daily life. Each individual, therefore, should be given the chance, training, technology, respect and encouragement to do so.

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Talking Politics: EMPOWERING COMMUNICATION AID USERS

Continued from page 8

they have to look at the board for relatively long periods of time while the user is putting together his or her message. People who use comunication boards may have their attempts to communicate ignored or find that people, even family members, cannot be bothered to use the board and shut it away. Part of the appeal of electronic communication aids seems to be that they reduce the effort and time required of people without disabilities as communication partners.

Jim Viggiano, a person with cerebral palsy who lives in an institution wrote:

"Half of the time I go to communicate some of the staff say, 'What the hell do you want?' or 'Get lost,' or 'I haven't got the time for that damn spelling board.' Some people have asked me questions and walked away before I point to a word to answer."

Most communication aid users, even those with very significant physical disabilities, still rate their communication difficulties as their most significant disability. Ruth Sienciwicz-Mercer wrote that:

"I have found that the most difficult aspect of my disability has been my lack of speech. People in the community at large have a tendency to equate one's speaking abilities with one's intelligence... The misconceptions on the part of those around a non-speaking person can be both painful and dangerous to that person, as it usually means he or she will be treated in a sub-human manner."

The varying ways in which speakers underestimate or misdiagnose people with significant speech impairments are summarized by Bob Counsell, who has severe dysarthria (difficulty in articulating words). He describes the different responses provoked by his speech:

"Whenever I meet someone new ... if I don't speak to them I offend them... If I do speak to them they react in one of four ways: they look at me in horror and think that I am mad; they shout at me thinking my impeded speech means I am also deaf; they hear my voice and begin to ask those around me questions which should be asked of me; or they speak to me as they would to a baby or a beloved family pet."

The perception of non-speakers as stupid is raised frequently. Writing in 1981 about community attitudes, Maree Ireland remarked that,

"especially with nonverbal people, there is still the assumption that we are people with less intelligence than themselves ... Like that saying 'Innocent until proven guilty,' we should adopt a saying 'Intelligent until proved unintelligent' without the need to prove it."

In 1996 Maree, now a lawyer, had the opportunity to explore current assumptions when she and some other Communication Aid Users Society (CAUS) members attended the memorial service for nine residents of a state institution who had died in a fire. Because the CAUS members had visible disabilities, they were presumed to be residents of the institution and a number of strangers came up and welcomed them with gracious condescension. Two people patted Maree on the head.

Evelyn Mosely, a communication aid user, found that when she lost her speech after an attack of encephalitis, more than her communication was disregarded:

"Meeting new people ... was a frustrating experience.... Even when they became aware of the communication board they would direct the conversation to the person with me, not to me personally, and they avoided eye contact. This was when the impact of the communication barrier really hit me. I had become invisible."

Sometimes it is better to be ignored — almost all non-speakers experience people talking about them in their presence. It is as if they are believed to be uncomprehending or unfeeling, if not deaf. At the age of 12, Anne McDonald heard a nurse say loudly that she would die from starvation in the next six months. At age 16, she was introduced to a middle-aged woman who said "If it was a puppy you'd knock it on the head, wouldn't you?". At age, 20, after *Sixty Minutes* screened a story about her, a viewer wrote in to say she should be killed. The interesting thing about this last comment was that the producer had no hesitation in putting it on the air, an action which would be almost inconceivable if she had been a member of another devalued group.

TALKING POLITICS

A significant social movement becomes possible when there is a revision in the way in which a group of people see a certain situation, they view it not as a circumstance that warrants charitable consideration, but as an injustice which is intolerable to society. The deaf community has produced many representatives who advocate for people who are deaf in general and complain of prejudice and discrimination - who perceive their problems as stemming from injustice rather than simply being the way things are for people with communication disabilities. What about non-speakers?

Not only has action by non-speakers not been documented in the same way, its absence has been noticed. In *Stigma*, Erving Goffman suggested that the sociological study of stigmatized persons was "usually connected with the kind of corporate life, if any, that is sustained by those of a particular category." He cited any group of people who lack speech as a group "whose peculiarity apparently discourages any group formation whatsoever" (Goffman, 1968:

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Talking Politics: EMPOWERING COMMUNICATION AID USERS

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33-4). In the 1960's, before the introduction of Blissymbols (graphic symbol language or pictographs) and the development of electronic communication aids, this would have been a fair comment, as without advances in communication techniques and technology it was then impossible for non-speakers to undertake group action. Any groups of people who lack speech would have consisted of individuals whose dysarthric speech was not understood by outsiders, and who were therefore not recognized as communicating.

By the 1980s enough non-speech people had obtained a means of verbal communication for it to be possible for them to form their own organizations. When the Communication Aid Users Society started in Melbourne, Australia in 1981 it was reportedly the first organization set up by and for non-speakers anywhere in the world, a milestone in the development of group identity. Interestingly, CAUS has remained an organization for those with significant communication disabilities associated with significant physical disabilities such as cerebral palsy and acquired brain damage. While there is nothing in the rules excluding people with diagnoses such as autism or Down Syndrome, the people most likely to use facilitated communication, this population has shown no interest in joining CAUS, possibly because information about CAUS has not reached them. The 1995 CAUS conference in Melbourne was also a landmark — the first national conference in Australia and possibly the world to be held by communication aid users rather than about or for communication aid users.

Speech disabilities associated with significant physical disabilities, in particular cerebral palsy, place great barriers in the path of political organization. Nonetheless, while the history of communication intervention with this group is very short (scarcely three decades), the first people with significant communication and physical disabilities from birth are now educated adults with jobs and children. Having succeeded in the terms of the wider society, they have the skills necessary for effective lobbying, if they choose to use them.

Unless we can establish an over-riding right to communicate -- encompassing the right to accurate diagnosis and early intervention, the provision of communication aids as a matter of right, and access not just to therapy, but to mainstream education ... we will find ourselves reaching a dead end.

A lucky few will get the communication aids and education necessary to achieve their potential, a larger group will get limited vocabulary communication aids and limited education -- enough to complain but not enough to succeed -- and the majority will get so little in the way of communication and education that they will never be able to complain.

Recent developments in mainstream communication technology, particularly in Internet access, have allowed non-speech people to connect to an extent which has not been possible previously. There is now an international community of articulate, active non-speakers who interact through ACOLUG, the Augmentative Communication On-Line Users Group. While every non-speech person certainly does not have access to the Internet, more augmentative and assistive communication (AAC) users are already connecting through ACOLUG than have ever been able to meet together, and they are sharing information and discussing advocacy issues around the world. This is a real opportunity for group formation, but one which as yet has not been taken up by FC users.

The first moves to establish a right to communicate started in the late eighties. In the United States, AAC user Bob Williams tried to make the connections necessary to create a movement for non-speakers' rights through *Talking/Politics*, a newsletter for people interested in thinking together about communication rights, set up in 1989 by Mayer Shevin. Williams said that:

"In the words and deeds of Anne McDonald and others with severe disabilities worldwide, we can hear the makings of a clarion call if we choose to listen. It is a clarion call to action similar to one issued nearly a decade ago. In 1979, the Centre for Human Policy helped stir many of us to action by calling for a universal community imperative. Ten years later, the typical life experiences of people labeled severely or profoundly disabled demand that we take another step closer to true community.

One way we can do this is by issuing a communication imperative which affirms and asserts that: Every person, regardless of the severity of his/her disabilities, has the right and the ability to communicate with others, express every day preferences and exercise at least some control over his or her daily life. Each individual, therefore, should be given the chance, training, technology, respect and encouragement to do so."

Williams used words familiar from the American civil rights movement:

"December 15, 1991, will mark the bicentennial of the ratification of the Bill of Rights, and its First Amendment guarantee of free speech. In the nearly two hundred years since the First Amendment's adoption, freedom of expression has gone on to be recognized not only as a fundamental right but a prerequisite to the full enjoyment of all other civil and human rights. However, for far too many Americans, freedom of expression remains an unrequited right at best: an American ideal which has yet to be fully realized."

He sought to build an organizational base for communication rights by mobilizing "persons with significant speech disabilities to work in close alliance with our families, friends, and all other supporters of the First Amend-

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Talking Politics: EMPOWERING COMMUNICATION AID USERS

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ment throughout the nation to realize free expression as a real right at long last."

Anne McDonald gave a presentation at the 1992 TASH disability conference in San Francisco entitled, The Right to Communicate, in which she proposed the establishment of "a right to communicate in formal situations such as courts, hospitals and schools" because "without such legally enforceable rights, people without speech will be at the mercy of decision-makers who can arbitrarily refuse to allow communication." Her words formed the basis of a resolution passed by TASH in 1993 and widely-promulgated in the U.S. (but virtually unknown in Australia).

NEW VOICES

As successful lobbying and networking, especially for non-speakers, require academic skills if not formal qualifications, one would expect activism to follow education. Sue Rubin -- a Lightwriter (an augmentative communication/conversation device) user who started to type with facilitation, graduated from high school in Los Angeles and has taken Cesar Chavez, the organizer of farm workers, as her role model -- may be the wave of the future. She uses e-mail to communicate with other people with autism and writes that "'Using Chavez as a model, I must organize autistic people who are able to communicate, to advocate for our human rights, and bring abusive situations to the public light..." She is realistic in her recognition "that people will not make changes in the condition of the disabled only because it is the right thing to do" but asserts that "advocates can fight a world indifferent to our needs." Rubin, who was once assessed as having an IQ of 24, recently won a major university scholarship in open competition and received a letter of congratulation from President Bill Clinton. Not only her words but also her achievements are agents for change.

Twenty-five years ago Bob Williams (former U.S. Commissioner for the Administration on Developmental Disabilities and the first non-speaking person in the world to head a government department), Rick Creech and other successful AAC users and advocates were the same age as Rubin is now. They blazed a trail which many other people with significant communication disabilities have followed. Sue Rubin, Lucy Blackman, an FC user who has recently graduated from a university, and others like them may do the same for those who need facilitation in order to communicate. As Matthew, "a voice of autism, no longer silent" wrote: "No disadvantaged group in man's history has improved their lot without being heard. Our situation is no different."

We live in an age of rapid technological change and communication, an age with the capacity to provide the mute with voices and spread the news around the world within a day. But those who are mute have a significant social role based on their disabilities — they provide employment for large numbers of professionals, professionals trained to assess, teach or nurture people with significant disabilities. Consequently, their push for rights and autonomy is not only likely to meet resistance from those who don't know them -- politicians, bureaucrats, the general public — but from those who do — their teachers, nurses, carers and parents — those who believe they know what's best for them.

Unless we can establish an over-riding right to communicate, encompassing the right to accurate diagnosis and early intervention, the provision of communication aids as a matter of right, and access not just to therapy but to mainstream education, and ultimately to employment, we will find ourselves reaching a dead end. A lucky few will get the communication aids and education necessary to achieve their potential, a larger group will get limited vocabulary communication aids and limited education — enough to complain but not enough to succeed — and the majority will get so little in the way of communication and education that they will never be able to protest.

Recent developments in mainstream communication technology, particularly in Internet access, have allowed non-speech people to connect to an extent which has not been possible previously. ... While every non-speech person certainly does not have access to the Internet, more AAC users are connecting than have ever been able to meet together, and they are sharing information and discussing advocacy issues around the world. This is a real opportunity for group formation.

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For more information on the work of the Facilitated Communication Institute, visit the FC Digest web site at <soeweb.syr.edu/thefci/>

The article's author, Rosemary Crossley, Ph.D., is director of the DEAL Communication Centre, Inc. in Caulfield, Australia. Dr. Crossley may be contacted by e-mail: <dealcc@vicnet.net.au> or you may visit the Centre's web site at <http//www.vicnet.net.au/~dealccinc>

Keys Towards Promised Land of Free Expression

BY LARRY BISSONNETTE

Larry, an artist in Winooski, Vermont, uses facilitated communication to help him combine words with his art to express his thoughts and ideas. Larry spent over ten years living in Vermont's Brandon Training School, a state institution for people with developmental disabilities. Some of Larry's drawings and paintings appeared in the March 1999 TASH Newsletter.

"Let me mention that it's practically getting possible to create a satisfying life, interesting and meaningful nowadays, because the popularity of institutions slides towards underground storage at a pace faster than police chasing escaped prisoners.

Going back in desolation where it's only me and letterless walls is not pleasant to think about. Nothing 'apartheids' you like the insensitive world of institutional existence. It's politically correct to say that kind people, needing gratification for giving, started the impetus for building structurally sound, yet inhumane institutions. I made my first preparations of a meaningful dinner of meat and potatoes in pristine-like, rurally remote, planned-as-a-farm, Brandon Training School. My leap into the pond of painting happened there. Knowledge and learning of art have allowed my abilities to soar out on an airfield occupied by people who don't have disabilities. Nearly 20 years have lodged in my memory, skating on icy surfaces of slippery thoughts and fears about trials of oppression on my personal vision of life. Now work should begin on repairing damage of the past.

You lend great sums of money for places like military mansions and meeting rooms for polygamous politicians. New lots of land for masses of people with disabilities need an outpour of organized funding for learning, artistic development, and learning to play sports. One soldier fighting persecutionary attitudes is little deterrent. March with me. You'll make valiant strides of promise, creating great havoc with nearly perfect brushstrokes to inspire you."

We're looking for YOU!

TASH is working to identify a list of people who have been members since the organization's inception in 1975. If you are one of these loyal members, please contact Nancy Weiss by phone (410-828-8274, ext. 101), e-mail <nweiss@tash.org>, fax (410-828-6706) or mail (see back cover for TASH's address).

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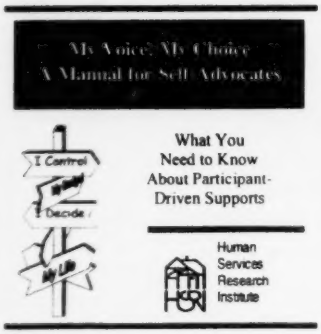
Self Determination and Participant-Driven Supports

My Voice, My Choice: A Manual for Self-Advocates


My Voice, My Choice
A Manual for Self-Advocates
I Control
I Decide
What You Need to Know About Participant-Driven Supports
Human Services Research Institute

By John Agosta, Kerri Melda & Cathy Terrill

Due to funding limitations and service wait lists the developmental disabilities field is changing. Adding to the changes are evolving service practices, including commitments to self-determination, community integration and participant-driven supports.

Whatever the changes in your state, self-advocates must influence events. *My Voice, My Choice* is a must-have curriculum. Use this manual to provide self-advocates with the information they need to help shape the service system. Use it also with family members, board members and service staff.

Eight chapters include basic definitions and concepts about how service systems work, along with explanations of participant-driven supports and managed care. Strategies to analyze a state system and influence change are also covered.

Loose-leaf binder includes: (1) over 170 pages of plainly worded text and study exercises, (2) overhead slides for each chapter (actual transparencies not included).

List Price: curriculum & overheads - $179; curriculum only - $120; overhead templates only - $60.

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The Serena Merck Memorial Award

for Innovation and Dedication in Practice

Purpose of the Award: The Serena Merck Memorial Award is given annually to an exceptional individual who has demonstrated long-term, selfless dedication and compassion in the care or service to children who have mental retardation and significant mental health needs. Mrs. Merck recognized the critical importance of what quality day-to-day care provided by committed individuals can make to children with cognitive and behavioral disabilities. The John Merck Fund has established this major, national award to honor her long-standing commitment to this field, and to call attention to the invaluable role caring individuals play in it.

Criteria for Selection of the Awardee Prospective awardees should meet one of the following categories: (1) Provides, as an employee or volunteer, services for children who have mental retardation and significant mental health needs. (2) Demonstrates long-standing commitment and innovative care of this population which has positively affected their quality of life and/or life opportunities.

Submission Guidelines: Organizational entities may nominate prospective awardees. One nomination per organization is permitted, although multi-service organizations may submit one nomination from more than one service unit. No self-nominations are acceptable. Only organizations serving children with mental retardation and significant mental health needs are eligible to nominate an individual. A 500-word summary of the reason the candidate is nominated, length of service in the field, and a description of the person's impact on children with mental retardation and significant mental health needs is required. At least two, but no more than five, accompanying letters of reference from individuals well qualified to evaluate the candidate's suitability for the award should be provided.

Nominations should be mailed before September 15, 1999, to:
Mr. Frank Hatch, The John Merck Fund,
11 Beacon Street, Suite 1230, Boston, MA 02108

Award: A $5,000 cash award and plaque will be presented to the awardee at the 16th Annual National Association for the Dually Diagnosed (NADD) Conference held November 10-13, 1999, in Niagara Falls, Canada. The awardee's travel expenses to the conference will be covered.

Highlights of Summer '99 Board Meeting

Continued from page 3

take on this role with the Integrated Employment and Careers Committee.

Textbook of JASH Articles on Inclusion: Nancy Weiss and Doug Fisher, Chair of the Education Committee, have completed a survey of professors to identify the JASH articles related to inclusion that they assign to their students most frequently. A book that contains these articles and related *Newsletter* articles is being planned.

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TASH Annual Conference in Chicago!

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Whether you've participated as a volunteer before, or would like to do so for the first time,

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If you are interested, please contact
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Come to the TASH TECH session
T-5 Functional-Contextual Assessment & Portfolio Design

So long to our dear friend and colleague, Marcie Roth!

As Marcie prepares to assume new challenges that will take her away from us on a daily basis, we take comfort in the fact that she will not only remain a staunch advocate and activist for disability rights in her new position with another national disability organization, but that she will remain a friend to, and an active member of, TASH. We asked Marcie to share a few thoughts as she prepares to embark on the next phase of her 20+ year journey in the disability movement.

Marcie enthusiastically helps to put the 104th Congress to eternal rest at the 1996 TASH Annual Conference in New Orleans.

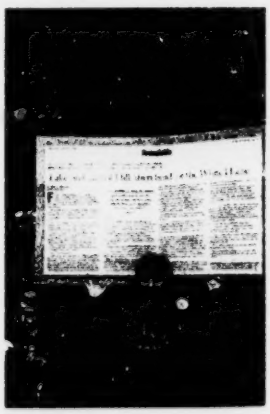
On August 6, 1999, I will leave my position as TASH's Director of Governmental Affairs and Public Policy to assume the position of Director of Advocacy and Public Policy for the National Council on Independent Living (NCIL). The decision to leave my position was very difficult. I will not really be leaving TASH though, as I intend to remain an active member of the organization I first joined in 1983. In fact, I have already accepted responsibility for chairing the governmental affairs strand at the 1999 TASH Conference and would welcome the opportunity to run for the TASH Board in the future.

Fortunately, my work with NCIL will continue to be relevant to the members of TASH, and I intend to do all I can to further the growing partnership between TASH and NCIL. For those of you who are unfamiliar with NCIL, it is the national association that represents most of the 500+ Independent Living Centers and 55 Statewide Independent Living Councils across the country. In my work with NCIL, I will spend a great deal of my time on Capitol Hill, and will be very active in the public policy issues that have an impact on people with disabilities. Rest assured that the mission of both organizations is so much in alignment, that my work for NCIL will likely have a positive impact on the membership of TASH.

Marcie with members of the successful collaboration that became the IDEA Working Group.

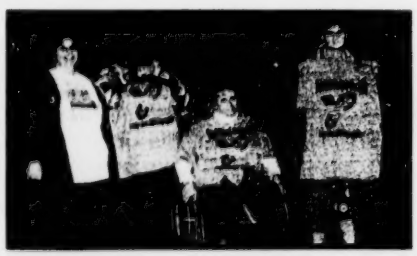
I'm pleased that Dan Dotson will be staffing TASH's governmental affairs and public policy office in an acting capacity. For those of you who don't know Dan (our current webmaster, office computer guru and winner of the quickest wit in the office award on a daily basis), I expect that you will discover that, in addition to his web management skills, Dan is a strong advocate for sound disability policy. Dan is one of those community leaders who has his finger very firmly planted on the pulse of the policy makers both in Washington and in the states. As the parent of a child with a disability, Dan brings first-hand, front-line knowledge to the public policy aspects of TASH's work.

I will miss the daily interaction with my dear friends, the incredible staff of TASH. I will also miss the connections with members of TASH with whom I have had the pleasure to work over the past four years. I look forward to being at the 1999 TASH Conference in Chicago with my fellow members of TASH.



Marcie effectively engages in one of the activities for which she has become well-known in the movement -- advocacy in action! Here, she is seen demonstrating at the White House with Maryland ADAPT activist Gayle Hafner.

L-R: Priscilla, Rose, Denise and Marcie share their first experience working together on a TASH annual conference (San Francisco, 1995).



L-R: Marcie with Lois Curtis, Linda Anthony, and Elaine Wilson at a Supreme Court demonstration. Lois and Elaine are the named plaintiffs in the original *Olmstead* lawsuit.

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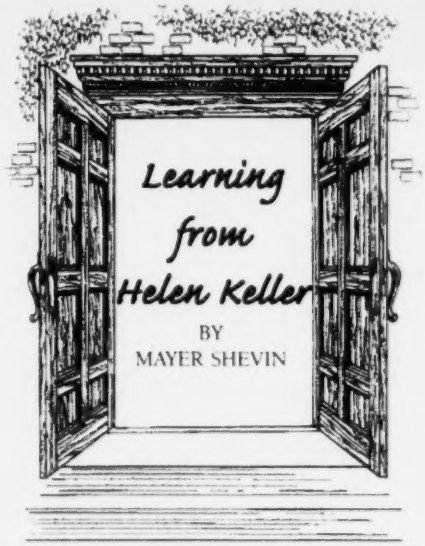


Helen Keller is probably the most universally recognized person with disabilities of the 20th century. (Others such as Franklin Roosevelt were equally well-known, but Keller is remembered primarily for her accomplishments which are disability-related.) Those of us who have grown up in the last half of this century have only known Keller as a figure of veneration. We know her primarily through popularized versions of her life such as the play "The Miracle Worker," or through her autobiographical works such as *The Story of My Life* (Keller, 1961 [1902]) and *The World I Live In* (Keller, 1908). Most of us have come away with the image of a more-than-human person living with the blessed support of an equally superhuman mentor, Annie Sullivan Macy.

There is little wisdom, however, to be learned from the stories of superheroes. It is from observing the struggles, losses and compromises in both Keller and Sullivan's lives that we are likely to find parallels to the everyday experiences of ourselves and our friends. Dorothy Herrmann's recent biography of Keller, *Helen Keller: A Life* (Herrmann, 1998) creates a much more complete picture of the costs of Keller's celebrity and iconic status, and of the tensions present in her life-long relationship with the woman whom she always referred to as Teacher. In this article, I will discuss two important themes from Helen Keller's life in terms of their implications for those of us who are also part of a community of people engaged in the enterprise of finding their voices in the world.

Keller and The Perkin's School

Helen Keller was born in Alabama in 1880, and became deaf and then blind following an illness when she was 19 months old. Annie Sullivan came to Alabama to work as Helen's teacher in March, 1887. Scarcely a month later, on April 5, 1887, came the well-known moment at the water-pump, where Helen first associated the objects she experienced with the words being spelled into her hand. Within the next year, Helen began keeping a journal, and was studying the poetry of Longfellow, Whittier, and Oliver Wendell Holmes. By the time she was ten years old, Helen Keller was literally world-famous. As early as October, 1888, she was writing letters to Michael Anagnos, the director of the Perkins' School for the Blind.

Anagnos, the man responsible for connecting Annie Sullivan with the Keller family and an eager promoter of the interests of the Perkins' School, where Sullivan had been both a student and a teacher trainee, was effusive in his description of Helen Keller in the Perkins' School's 1888 annual report, published little more than a year after she began to communicate:

> *...as if impelled by a resistless instinctive force she snatched the key of the treasury of the English language from the fingers of her teacher, unlocked its doors with vehemence, and began to feast upon its contents with inexpressible delight. As soon as a slight crevice was opened in the outer wall of their twofold imprisonment, her mental faculties emerged full-armed from their living tomb as Pallas Athene from the head of Zeus.* (Quoted in Herrmann, 1998, p.64).

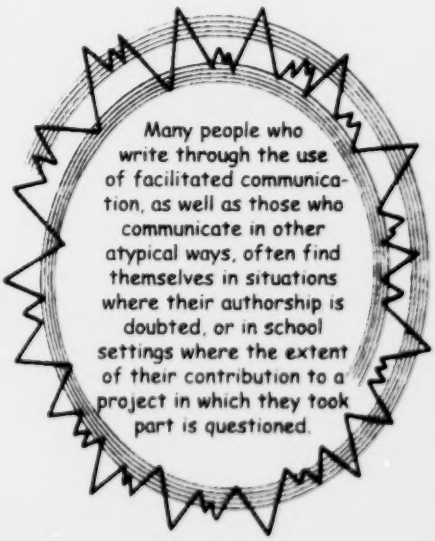
In subsequent years, Anagnos wrote at length of Keller in the school's annual report, with each report more glowing and, it must be said, more exaggerated than the last — 146 pages were devoted to her in the 1889 annual report:

> *...She is the queen of precocious and brilliant children, Emersonian in temper, most exquisitely organized, with intellectual sight of unsurpassed sharpness and infinite reach...* (Quoted in Herrmann, 1998, p.75).

These are heady words to describe a nine-year-old child, even one of Keller's remarkable accomplishments. Although Keller and Sullivan were developing a wide circle of influential friends among the rich and famous of Boston, resentment was growing over the preferential treatment Keller received at the Perkins' School. Morever, suspicions were growing of how real Keller's accomplishments were, since no teacher of deaf-blind students had ever showed the same success that Annie Sullivan had seen in her brief time with Helen.

The "Frost King" Incident

In November, 1891, Helen sent Anagnos a birthday gift: "The Frost King," a fairy tale she had written for him on her braille slate. Anagnos was delighted with the story, and reprinted it in *The Mentor*, the Perkins' School's alumni magazine. It was soon reprinted to great acclaim in a weekly publication of the Virginia Institution for the Education of the Deaf and Dumb and Blind; however, the editors of that journal were soon informed that Helen's story was remarkably similar to a story published in a book of fairy tales by Margaret T. Canby. Anagnos looked into the situation, and discovered that, during the previous year, when Helen had been visiting at a friend's home, she had probably been read the story in Annie Sullivan's absence. When he questioned Helen


Many people who write through the use of facilitated communication, as well as those who communicate in other atypical ways, often find themselves in situations where their authorship is doubted, or in school settings where the extent of their contribution to a project in which they took part is questioned.

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through an interpreter, however, she told him that when she had written "The Frost King," she believed it to be an original story. Ten years later, in *The Story of My Life*, Keller would write:

> *...how could it possibly have happened? I racked my brain until I was weary to recall anything about the frost that I had read before I wrote "The Frost King;" but I could remember nothing, except the common reference to Jack Frost, and a poem for children, "The Freaks of the Frost," and I knew I had not used that in my composition.*
> (Keller, 1961, p. 65.)

Anagnos at first believed Keller had made an innocent mistake. Some months later, however, in response to an accusation by one of the Perkins' teachers that Helen had told her the story had been read to her very recently by Annie Sullivan, Anagnos decided to convene a "court of investigation." The court was composed of eight school officials, four of whom were blind, and Anagnos. Keller described the circumstances: with Annie Sullivan out of the room, Keller was

> *...questioned and cross-questioned with what seemed to me a determination on the part of my judges to force me to acknowledge that I remembered having had "The Frost Fairies" read to me. I felt in every question the doubt and suspicion that was in their minds, and I felt, too, that a loved friend was looking at me reproachfully, although I could not have put all this into words.... As I lay in bed that night, I wept as I hope few children have wept. I felt so cold, I imagined I should die before morning, and the thought comforted me. I think if this sorrow had come to me when I was older, it would have broken my spirit beyond repairing.*
> (Keller, 1961, p.66).

At the time, Helen was 12 years old. The support of those who could be forgiving of a child's confusion about the nature of plagiarism was of little avail.

> *Miss Canby herself wrote to me kindly, 'Some day you will write a great story out of your own head, that will be a comfort and help to many.' But this kind prophecy has never been fulfilled. I have never played with words again for the mere pleasure of the game. Indeed, I have ever since been tortured by the fear that what I write is not my own. For a long time, when I wrote a letter, even to my mother, I was seized with a sudden feeling of terror, and I would spell the sentences over and over, to make sure that I had not read them in a book. Had it not been for the persistent encouragement of Miss Sullivan, I think I should have given up trying to write altogether.*
> (Keller, 1961, p.68).

The mystery was eventually "solved" when it was determined that Keller had very likely been read Canby's book more than two years before she wrote the story down, during a brief period when Annie Sullivan was away recuperating from an illness.

The events surrounding this episode left a long-lasting mark on Keller. She wrote in her autobiography that, a year later,

> *...I was still excessively scrupulous about everything I wrote. The thought that what I wrote might not be absolutely my own tormented me. No one knew of these fears except my teacher. A strange sensitiveness prevented me from referring to "The Frost King", and often when an idea flashed out in the course of conversation I would spell softly to her, "I am not sure it is mine." At other times, in the midst of a paragraph I was writing, I said to myself, "Suppose it should be found that all this was written by someone long ago!" An impish fear clutched my hand, so that I could not write any more that day. And even now [1903] I sometimes feel the same uneasiness and disquietude* (Keller, 1961, p.71).

Why was this young girl subjected to such an inquisition? Was she the only young student at the Perkins' School to ever produce writing which closely copied someone else's work, claiming it for her own? Very likely she was not; any teacher knows such an event is common in children her age. However, she was the only student described in the Perkins' School's reports as the "personification of goodness and happiness" (Herrmann, 1998, p. 75). Clearly, the energy which had been used to celebrate and lionize her far beyond her actual accomplishments was quickly turned against her when she did not fully live up to those unrealistic expectations, expectations which were neither hers nor those of her teacher.

According to Herrmann, Keller may also have been a secondary victim of jealousy

and ill feelings directed toward Annie Sullivan by other teachers at the Perkins' School. Sullivan was not a "team player"; she was a proud woman who claimed sole responsibility for the breakthroughs she had achieved with Helen Keller, to the annoyance of teachers and administrators at the Perkins' School. This isolation of both Keller and Sullivan from the broader school community may also have contributed to the vehemence of the investigation directed against them both.

Helen and Annie's Life-long Interdependence

Annie Sullivan came to work with the Keller family in Alabama in 1887. She and Helen were almost constant companions until Sullivan's death in 1936. Their close connection continued through the entire duration of Sullivan's marriage to, and separation from, John Macy, a socialist author and political activist. It survived deep differences in personality between Keller's even-tempered nature and Sullivan's irascibility and mercurial mood swings. Keller became an active participant in both the Swedenborgian church and radical politics, both of which Sullivan viewed with distaste.

During this time, Keller remained a well-known public figure; she was a major spokesperson for the American Foundation for the Blind, and the subject of a 1918 movie based on her life, *Deliverance*.

Undoubtedly, Keller lived a life of widely varied experience, pursuing her own interests beyond those of her teacher. However, her connection with Sullivan remained the central "fact" of her life. This joining of lives seemed in many ways to be tremendously fulfilling for both of them. It is instructive, however,

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to read of the course of Keller's life following Annie Sullivan's death.

Polly Thompson was part of their shared household since 1914. However, she became Helen's trusted companion only by default, as, during the 1930's, Annie Sullivan's health and remaining vision declined. After Sullivan's death, Polly Thompson assumed the role of Keller's constant companion until she, too, died in 1960. However, whereas Annie Sullivan had usually allowed Keller to take the lead in determining the course of their shared existence, Thompson tended to be far more controlling. And whereas the habit of relying on a single person as her primary connection with the wider world had served Keller well for most of her life, it placed her in a position of great vulnerability when Sullivan was no longer there.

By the mid-1950's it had become obvious to their friends that Polly's behavior toward Helen was "bordering on madness." For years it had been Polly who dressed Helen, a long and tedious job because Polly was such a perfectionist about Helen's public image. Lately, Polly had become even more fanatical about Helen's appearance. Because she insisted that Helen look her best, even with her closest friends, it was now a burden for them to have company. Spur-of-the-moment visitors, whom Helen might have enjoyed seeing, were told that Polly and Helen could not see them. As a result Helen was even more isolated. What deeply disturbed members of their intimate circle, however, was that even though Nella, Katherine Cornell, Nancy Hamilton and Lenore Smith all knew the manual finger language, Polly would not let them spell to Helen when anyone else was present. Still a prisoner in her old age, Helen was cut off from contact with anyone but her senile, possessive companion (Herrmann, 1998, p. 312).

Lessons from Keller's Life

As we search accounts of Keller's experiences for guidance in negotiating relationships among facilitated communication users, their facilitators and other supporters, and the broader community, it is possible to err in both the direction of over- and under-identification. Certainly the major differences between the circumstances of Keller's life and those of anyone growing up with a disability a century later must not be overlooked. However, there are instructive, sometimes disturbing resonances between Keller's life and those of people today who rely on some level of support for their communication.

*1. **Responsibility for one's words.*** Many people who write through the use of facilitated communication, as well as those who communicate in other atypical ways, often find themselves in situations where their authorship is doubted, or, in school settings, where the extent of their contribution to a project in which they took part is questioned.

The scrutiny under which their words come may be related to the novel means by which the communication takes place, or to the presence of support people. However, it may also be related to the cognitive dissonance experienced by people in authority whose categories of people do not yet include "somebody who (looks/acts/grew up) like *that* and writes like *this*." One example of this is the African-American, Phyllis Wheatley, whose book of poetry published in Boston in the 1770's was widely seen as a hoax by people who could not conceive of a former slave writing classical poetry (Shevin, 1993). Keller represents another such example, and many individuals within the community of facilitated communicators have found themselves under similar scrutiny.

Another side of this issue, however, can be seen in Keller's acknowledged ongoing confusion over the "Frost King" story. At the time of the story's wide dissemination, Keller was eleven years old; she had been a part of the broad community of communicators for less than four years, and her access to that community had been mediated *almost* exclusively by a single person, Annie Sullivan. Since Sullivan had been Keller's near-constant companion throughout that period, she was presumed to be in a position to easily confirm whether Keller had ever seen the book from which "The Frost King" was apparently plagiarized. Under these circumstances, we can guess that Keller may never, until the time of this incident, have been required to *assume responsibility* for that which she wrote. Taking responsibility for one's words is a skill learned so early by most people that we sometimes give it little thought, but it is a learned skill. Being able to say whether something actually happened to me or whether I imagined it; saying whether I wrote something myself, wrote it with another's help, or heard it elsewhere; and being clear whether I am reporting my own experiences, thoughts and desires, or those I think my listener wants or expects to hear — all of these forms of *responsible communication* are established over time. The lessons may be learned though observation and conversation, or by trial and error; they are sometimes learned through punishment and tears. But to truly learn these lessons, one needs an element which Keller lacked: *multiple communication partners.*

Sullivan was a constant in Keller's life, and could always be relied upon to coach and correct Keller in grammar, polite address, accuracy of fact, and so on. I would argue, however, that Sullivan's consistent presence prevented Keller from learning to take responsibility for her own words.

Is this an inevitable occurrence in the lives of people who require support or mediation for their communication? Probably not — Keller herself clearly mastered such responsibility later in her life, though not before she had been scarred by the effects of its early absence. In hindsight, we can speculate on approaches which might have helped Keller gain such mastery early on; early attention to these issues, and explicit instruction in the rules of discourse appropriate to someone in the public eye both might have helped. Most important, however, would have been both ongoing contact with multiple support persons, conversational and instructional partners, and practice in the communication of accurate information to and among multiple communication partners. "Message-passing" is not just a tester's tool; it is also a skill thats use is a mark

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of a responsible citizen of the community of discourse.

2. *The downside of interdependence.* Was Keller the beneficiary or the victim of her lifelong relationship with Annie Sullivan? Nobody reviewing Keller's long list of accomplishments and accolades, famous friends and unique experiences could doubt that Sullivan devoted herself wholeheartedly to opening doors for her student and intimate companion, or that

Those of us who are supporters and allies of FC users can play an important role in helping our friends come into possession of their power and full citizenship in our community. The most powerful acts -- and often the most complicated and painful ones -- by which we can support movement in this direction, are those acts by which, a piece at a time, we become less and less indispensable.

Keller was immeasurably enriched by the experience. However, that unique intertwining of two lives became the only way Keller would know of being in the world. She came to experience the world only in partnership, and seemed powerless to step back from such a partnership even when, as during her years with Polly Thompson, the partnership had become a prison. Far from being interdependent with, and a full participant in, a community, Keller had become interdependent with a particular person. As a result, her life experiences expanded or shrank depending on that specific person's situation and inclinations.

Was this degree of *exclusive* interdependence inevitable? Although we cannot judge the participants in this encounter or the times they lived in by current standards, we can draw on Keller and Sullivan's experiences as we reflect on our own.

One question worth exploring is this: who was responsible for the exclusivity in Keller and Sullivan's relationship? Clearly, both women sought it out through most of their lives together. Not only was Sullivan Helen's only teacher, Helen Keller was Ann's only student. Each defined themselves in relation to the other. Sullivan's marriage was followed by separation after a few years; Keller, though once caught up in a tempestuous romance which nearly led to an elopement, apparently turned away from that moment in her life with few regrets. Both women chose the relationship, but in a real sense, Sullivan can be said to have been *responsible* for it. It was at least theoretically within her power to expand Keller's access to a wider range of readers, signers and teachers; to become a transparent conduit, a "non-player," in Keller's interactions with others; and to systematically welcome interactions in Keller's life in which she did not participate, rather than viewing such events as dangerous moments to be avoided.

Although the habits of both women created a stable life for both Keller and Sullivan during Sullivan's lifetime, Annie Sullivan may have already come to doubt their wisdom before her death.

A short time before Annie died, a friend, meaning it as a compliment, had told her, "Helen would be nothing without you." "Then my life has been wasted," Annie said (Herrmann, 1998, p.257).

* * * * *

For facilitated communicators, their facilitators, friends and allies, these observations may point toward an exploration of our own habits. Each of us might ask ourselves: are we settling into a comfortable symbiosis with our communication partners, in which communication not only *coexists* with friendship and intimacy, but *relies* on it? If so, what steps can we take to disentangle these two important features of our lives? For although it is important for each person to have intimates with whom we can trustingly share our dreams and heartaches, it is no less important to be able to communicate impersonally with our physician, our congressional representative, or the person from whom we are ordering a pizza.

It is within the power of both facilitators and the family members or supervisors who oversee them to help create more expansive, rather than symbiotic, communicative relationships. Continually recruiting novice facilitators into a person's life is far preferable to a reliance on a stagnant pool of limited resources. When new facilitators are added to a foundation of already existing facilitator support, most facilitated communicators come to welcome, with confidence, the challenges presented while breaking in new staff. And for facilitators, the partnership with either newer or more experienced facilitators, other communication partners and allies is a significant part of keeping our skills honed, our direction clear and our efforts sustainable. Individual facilitators can take the initiative in expanding the circle; the effort is helped immeasurably when it becomes a priority of those who train facilitators, for administrators who provide access to enriched staffing resources, and for allies involved in connecting an individual with his or her broader community.

The world will never see another Helen Keller. Those visible people with disabilities of our generation do not stand alone and unique — increasingly, they are powerful members of a powerful community, in control of those who support them rather than controlled by them. Those of us who are supporters and allies of facilitated communication users can play an important role in helping our friends come into possession of their power and full citizenship in our community. The most powerful acts — and often the most complicated and painful ones — by which we can support movement in this direction, are those acts by which, a piece at a time, we become less and less indispensable.

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The 1999 Executive Board ELECTION

BUILDING TASH LEADERSHIP

Now is the time for you to decide who will help provide critical leadership in TASH's social justice movement for people with disabilities. Many important issues and challenges face us - your participation as a voting member of TASH counts more than ever.

Five of the 15 seats on the TASH Executive Board will be re-seated at the December 1999 TASH Conference in Chicago. The individuals who appear on this year's slate have made significant contributions in the lives of individuals with disabilities and have demonstrated leadership in the disabilities movement.

Your vote is critical. Please use the postage-paid, self-mailing ballot provided on page 25, or clearly write "ballot" on the envelope you use. Ballots must be received at the TASH office by October 15, 1999. Please use ink and vote for five candidates. Voting for more than 5 nominees will invalidate your vote.

THE FOLLOWING ARE THE NOMINEES FOR THE TASH EXECUTIVE BOARD OF DIRECTORS:

Jeff Bassin
is the Director of Family Support Services at the Productive Living Board for St. Louis County Citizens with Developmental Disabilities (PLB). In this capacity he has had the opportunity to develop and provide guidance and technical assistance regarding a variety of services and supports that positively contribute to the quality of family life for families with a child (or children) with developmental disabilities.

Within several years after graduation (in the early 70's) from the George Warren Brown School of Social Work at Washington University in St. Louis, Jeff began working in support of and in collaboration with families who have children with disabilities. While employed at the St. Louis ARC, he developed a parent-to-parent support program for parents of newborn and newly diagnosed children with developmental disabilities, which was featured in Parent Outreach magazine. He also developed educational resources and training related to sexuality and persons with mental retardation.

Jeff is a member of the National Association of Social Workers and is recognized by that organization as a member of the Academy of Certified Social Workers (ACSW). In addition, he is credentialed in Missouri as a licensed clinical social worker (LCSW). He serves on several local university advisory committees and is a practicum instructor for the schools of social work at St. Louis University and Washington University. He is also adjunct faculty at Washington University's George Warren Brown School of Social Work, currently teaching a graduate level social work course on social work intervention with families who have children with developmental disabilities.

Jeff has served on the Board of Directors of the Missouri chapter of TASH (MO-TASH) since 1993. In 1996, he was elected President of MO-TASH and served in that capacity for one year. Additionally, he has presented at TASH conferences on such topics as inclusive leisure and adult socialization supports, and most recently on respite care as a critical family support.

Jeff shares in the value system embraced by TASH and is committed to assuring that our vision for persons with disabilities is not compromised. He desires to share his expertise as a clinical social worker and advocate for family support with the TASH membership. His view of family is a holistic one as well as strength based.

Wanda J. Blanchett
Wanda is an active TASH member who has boldly undertaken controversial issues of sexuality education, HIV/AIDS education, and issues related to meeting the needs of non-heterosexual individuals with significant disabilities. For over 15 years, she has worked in community and public school settings to promote the inclusion of individuals with disabilities in all facets of life. She has worked diligently as a direct service provider, teacher, and teacher educator to increase participation of individuals with special needs in their local communities and to improve educational programming and outcomes for people with disabilities.

Wanda's commitment to empowering persons with significant disabilities to determine their own destiny is informed by her work in the 1980s as a direct service provider for recently de-institutionalized individuals in the state of Arkansas. Specifically, she helped to facilitate their transition into independent living settings, employment, post-secondary education and all other aspects of adult life that were important to them.

Wanda is an advocate for inclusive education and quality educational programming for students with special needs. Her pledge to improving educational programming and outcomes of students with disabilities dates back to her classroom teaching experiences in the Delta region of Arkansas. As a practitioner, she taught students with disabilities in an elementary public school setting and served as a

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1999 BOARD ELECTION

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consultant to regular classroom teachers long before it was considered "best practice." She provided technical assistance to general education teachers that enabled them to meet the needs of their students with disabilities within the general education curriculum. Although Wanda found her role as a practitioner extremely rewarding, her desire to have a more direct impact on improving educational programming and outcomes of students with special needs led her into teacher education and research.

Wanda is currently an Assistant Professor in the Department of Exceptional Education at the University of Wisconsin-Milwaukee where she is involved in teacher preparation and research. Her research focuses on issues of sexuality, urban teacher preparation, and the role of race, class and gender in special education. Additionally, she has published several articles in special education journals and made a number of presentations at TASH and other professional conferences. She is currently co-chairing the sexuality strand for the 1999 TASH Conference.

Wanda is interested in serving on the Executive Board for three reasons: she would like to utilize her practical and professional experience to further the mission of TASH into the next century; she wants to ensure that TASH continues to be viewed as a leading advocacy organization that is committed to diversity in all of its many forms, and she would like to work within the framework provided by TASH to challenge attitudes, institutions and policies that prevent individuals with significant disabilities from expressing themselves and achieving their goals.

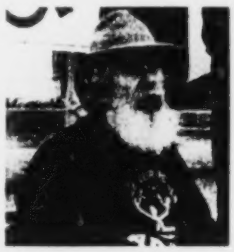
Kathy Boundy

Kathy, co-director of the Center for Law and Education, has an extensive background in education law based on providing legal support and technical assistance to attorneys and advocates representing low-income children and youth. An attorney with CLE for more than 20 years, Kathy has, in particular, played a significant role through legislation, policy development and litigation in implementing and enforcing the rights of students with disabilities, including to improved educational outcomes under the Individuals with Disabilities Education Act, as amended, and Section 504 of the Rehabilitation Act of 1973.

Kathy is co-author of CLE's Educational Rights of Students with Disabilities: A Primer for Advocates and numerous articles, most recently "Including Students with Disabilities in Standards-Based Education Reform" (1998).

Kathy has been a TASH Board member since 1996 and is a member of the TASH *Newsletter* Advisory Subcommittee.

Bob Kafka



Bob is a National Organizer of ADAPT, and Co-Director of the Institute for Disability Access in Austin, Texas. ADAPT/Institute for Disability Access does grassroots training and organizing to develop new activists in the disability community. Bob has been active in National ADAPT since 1984, and started ADAPT of Texas with Stephanie Thomas.

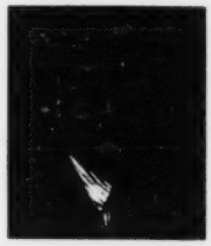
There have been a number of "firsts" throughout Bob's life and career. He began his work in the disability field with the local Coalition for Barrier Free Living in Houston, which became one of the first Independent Living Centers in the United States (Houston Center of Independent Living). Bob was the first President of the Board of Directors of the Houston Center of Independent Living.

Bob helped start the Coalition of Texans with Disabilities, which was one of the first cross-disability consumer run state coalitions. He later became a board member of the American Coalition of Citizens with Disabilities (ACCD). This national cross-disability consumer run coalition was instrumental in getting the 504 regulations promulgated in the late 1970's.

"There are two statements hanging above my desk that sum up why I want to be a board member of TASH - 'Do Something! Even If It's Wrong!' and 'Don't Mourn - Organize!' I fervently believe in People Power. Legislation is great. Legal action can be effective. However, our experience with how IDEA has been implemented at the local level, the lack of enforcement of Section 504 of the Rehabilitation Act, HUD's ignoring violations of the Fair Housing Amendments, the institutional bias of our long-term care system, the 75% unemployment rate among people with disabilities, and the constant attacks on the Americans with Disabilities Act have only re-enforced my belief that we need to be organized at the local level. If we are going to have the promises that were made in Washington D.C. become a reality in our lives and the lives of our children, we must take action to make local officials 'do the right thing.'

We must build the power from the grassroots up. People with disabilities, family members and advocates must make the commitment, focus our anger and demand change. TASH can assist in harnessing this 'People Power.' The TASH board can guide and influence direction, but ultimately if we don't act as a powerful community, all the disability laws and all the disability legal actions will not get the social change we seek. I've been involved in the disability rights battle for 25 years. My enthusiasm increases when new people join the fight. Ultimately those of us who have been involved with disability rights for many years will go to the 'disability rights graveyard' and our movement will need new blood to carry the flags of independence and interdependence into the 21st Century."

Ming-Gon John Lian



I feel extremely honored to be nominated for this year's election of new board members! I became a TASH member in the 1970s and was a member of the Texas-TASH while I was still a student. Early in the 1980s, I was encouraged by the TASH Board to join the effort of enhancing programs and activities relating to cultural and linguistic diversity in TASH. I will always treasure the opportunities I have had to serve as the chair of the Asian/Pacific Subcommittee (1984-1994), the chair of TASH Committee on Multicultural and International Issues (1989-1991), a member of the Community Living Committee (1987-present), a member of the Elections Committee (1990-1991), a reviewer for the TASH Conference (1989-present), and an ex-officio member of the TASH Board (1990-1991 and 1998-present). I have also actively participated in state chapter (Illinois-TASH) activities. I was a board member (1990-1993 and 1999-present), newsletter editor

Continued on page 23

1999 BOARD ELECTION

Continued from page 22

(1991-1993), and the chair of the Volunteer Committee at the IL-TASH Conference (1999-present).

The major reason I am a loyal member of TASH is because I believe in advocacy and justice for all individuals in an inclusive community. Being a faculty member in teacher education at Illinois State University, my commitment and effort to serve on the TASH Board will include sharing of my 20 plus years of TASH experiences, teamwork, and advancement of policies and services for under-represented persons, as well as promising practices in the school and community as we step into the new century."

Tia Nelis

"My name is Tia Nelis and I believe that all people should be treated as equals. People with disabilities should be respected for their individual dreams, talents and opinions. They want real jobs with real pay and benefits or, if they can't work in a paid position, they should be able to do meaningful volunteer work in the community. They want to have relationships, friendships and some people would like to get married. They want to be able to decide who works for them and to be able to hire and fire that person. They want to be able to choose how much support they need and don't want. They want to choose the agencies that give them services and to make sure that those places are monitored. They want to have control over their own money, or be able to choose who can help them manage their money.

I strongly believe that people can make their own choices and decisions. They want to serve on boards and committees that are making decisions about their lives as an equal member of that body, not as a token. They want to be involved in all the meetings that talk about the goals and dreams that they want in their lives. They want to be able to have a home or apartment and they want to choose if they want to live alone or with someone. They want to have fun, do social things and go on vacation. I know all these thingsbecause I am a self-advocate who has learned to advocate for myself and have been involved in supporting other people to help them make decisions in their lives.

Some boards and committees that I have been involved with are: Self-Advocates Becoming Empowered, Illinois Developmental Disabilities Planning Council, People First of Illinois, Community Support Services, Capabilities Unlimited, Inc., The Ray Graham Association, The Research and Training Center on Aging with Mental Retardation Advisory Board, National Down Syndrome Society Legislative Advisory Committee, National Center on Self- Determination, Committee for the Year 2000 International Self- Determination Conference, the Legislative and Social Issues Committee and the Self-Advocacy Ad Hoc Committee for the American Association on Mental Retardation. I am also the Chairperson for the national organization Self-Advocates Becoming Empowered, which is a national self-advocacy organization run by people with disabilities.

I have facilitated and participated in a leadership program to serve on boards and committees, and have served as a member of federal grant review teams for OSERS and ADD. These new roles for people with disabilities focus on leadership and advocacy skill development, and enhance programs that can and should provide meaningful services and employment opportunities.

Since 1993 I have worked for The University of Illinois at Chicago as their Self-Advocacy Specialist. Before that I worked at the YMCA in their childcare programs and for the Western DuPage Special Recreation Association with their day camp programs.

As a self-advocate serving on the TASH Board, I can help ensure the mission, goals and values of TASH. I will make sure that the voices of self-advocates across the country are heard and that TASH will continue to listen to and include self-advocates within the organization."

Liz Obermayer

Liz is a long-time leader in the self-advocacy movement. Working through the Boston Department of Mental Retardation, Liz actively works on behalf of the rights of self-advocates, including "providing leadership training and mentoring to people served by the department." Prior to relocating to Boston, Liz was active in her local self-advocacy group in New Jersey, served on the Board of New Jersey TASH, and worked with a state-wide group working on closing institutions. On the national level, Liz was the vice president of the national organization, Self-Advocates Becoming Empowered (SABE) from 1993 to 1996. Liz is also the co-chair of the National Advisory Group for Justice. This organization's mission is "to prevent discrimination against people with developmental disabilities in the criminal justice system, whether accused or victims of crimes, and to educate criminal justice professionals and people with developmental disabilities about one another."

Liz's work on behalf of people with disabilities earned her the Elizabeth Bogg Award for Young Leaders awarded by the President's Committee on Mental Retardation in 1998. Liz is a long-time member of TASH. She has been a Board member since 1996 and is Secretary of TASH Executive Committee and Co-Chair of the TASH Membership Operating Committee.

Barbara Ransom

Barbara Ransom is a legal advocate for persons with disabilities. Although she began her career in computer law, longtime disability rights activists and personal friends, Nancy Zollers and Frank Laski, persuaded her that disability advocacy needed her more. Barbara has practiced at the Public Interest Law Center in Philadelphia for nine years, using the ADA, IDEA and Section 504 of the Rehabilitation Act as leverage for the full integration of persons with disabilities.

Barbara's interest in disability rights and advocacy issues is also personal. She had two brothers with physical and learning disabilities. Although she was trained, certified and practiced as both a school teacher and a counselor, it was not until she entered the legal profession that she was able to understand and appreciate the successes that her brothers experienced in achieving their own independence.

Barbara is dedicated to continuing the PILCOP tradition of advocating for systemic change so that all people are valued. As a member of the TASH Board she hopes to increase TASH's involvement in the area of criminal justice and on the issue of including persons with disabilities as a protected group under the national hate crime bill.

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1999 BOARD ELECTION

Continued from page 23

Mike Remus

"I am honored to have my name submitted as a nominee to the board of directors for TASH. I have been involved with TASH from a distance and am now ready to become much more involved. I have presented at past TASH conferences as an educator and parent and have been a supporter and believer in this organization. If it were not for TASH we would not be seeing additional inclusive practices in the community. My sons are included in the community because of what I learned through TASH. For this I am grateful and am ready to help pursue more inclusive and best practices in schools and the community.

I could tell you that I have an extensive background in working with disability issues from a national and international perspective, but I want to spend my time giving you a sense of my beliefs and what I envision for TASH. If you want more information regarding the above please let me know and I would love to discuss this with you. You can reach me at The Arc of Tennessee in Nashville at 615-327-0294.

I believe the mission of TASH is to help people realize that our strength as a society comes not when we exclude people for their differences, but when we include them and embrace their diversity. We must teach society that what is important about people is their experience, their viewpoint and their humanness. Diversity brings richness to our lives and our society and has tremendous value. Disability is a piece of that diversity and should be accepted, not shunned.

How do we get society to this level of acceptance? Education is the key. It is up to us to show inclusive practices and demonstrate the success of this approach. As we are more accepting of self-advocates and show by the way we treat them that we welcome their contribution, we will demonstrate how necessary and valuable their presence among us is. The biggest barrier to our success in this area is attitude -- especially our own. Anything will work with the right attitude and we must be the shining example of how inclusive practices can succeed. At the same time, we must recognize that some people will need more education and more time to accept this philosophy. We must give them the time they need to understand our views, but never at the cost of sacrificing our beliefs and values.

As the premier disability organization in the world, TASH has an awesome responsibility to be the best it can be. In any organization, there is room for growth and improvement and we must recognize that we can only remain the best as we continue to learn and grow. We must look at change and embrace it -- not simply for the sake of change, but as an opportunity to achieve our mission and become better at what we do.

We can be proud of our past. TASH has envisioned an inclusive community for years and we have seen this come to some reality through the years. We have changed the world, but our job is not done until every individual with a disability is living, learning, working and playing in their own communities with the services and supports they need. As a strong believer in TASH and as the parent of two sons with disabilities who benefited from TASH's accomplishments and vision, I intend to be a part of the future for TASH. I want to help make the dream of inclusive communities a reality for all of us."

Colleen A. Thoma

"I am very honored to be considered for election to the Executive Board of TASH. I have been an active TASH member since 1987 when I first started supporting people with significant disabilities to be members of their communities. I worked in a variety of settings, and I learned much from the people I was teaching/supporting, including how to listen, how to advocate, how to help people achieve their goals. It was after the birth and subsequent death of my son due to multiple disabilities in 1989 that I began to view my work in a different light. I became a much stronger advocate for individuals with disabilities and their families, probably realizing its true necessity for the first time.

I am beginning my work in academia as an assistant professor in the Department of Special Education at the University of Nevada, Las Vegas. I have been there for two years, and currently serve as the coordinator for the program in teaching students with cognitive disabilities. I also have pioneered a graduate degree concentration in transition planning that will begin this fall. I am working on a grant-funded project from the Office of Special Education Programs, studying the best methods and strategies to prepare teachers to support student self-determination in transition planning. This project will expand upon other research in the area of self-determination in transition planning. Other research interests include alternative assessments, augmentative and assistive technology, and supported employment.

During these two years in Nevada, I have also been involved in a multitude of projects to impact the quality of community supports available to individuals with disabilities in Las Vegas. I serve on the board of directors for two community agencies that provide vocational supports to adults with disabilities. I work with a local elementary school as a parent/community member of their site-based management team. I am the President of the local TASH chapter, TASH-Southern Nevada (SN) and was a founding member of the Nevada chapter in development of the Association for Persons in Supported Employment (APSE). I chaired the Nevada Community Inclusion Conference, which brought experts from around the country to Nevada to help with training in best practice procedures such as positive behavior supports, natural supports, community bridge-building, conversion, and self-determination.

TASH-Southern Nevada has been actively advocating for the use of positive approaches and the subsequent prohibition of aversive techniques with individuals with disabilities. Much of the work that I have been involved in for the past year has centered around this issue. Our efforts resulted in the passage of Assembly Bill 280, which mandates the use of positive behavior supports for people with disabilities, in all settings, for all age groups.

TASH-SN also scheduled the first positive behavior support training institute to provide teachers, adult support staff, and other advocates with information about how to begin to implement these strategies. I plan to continue to support individuals with disabilities and their families through a multitude of direct and indirect means. I hope to advance this agenda through even greater participation with TASH as an executive board member. Thank you for this opportunity."

TASH 1999 Election of Five (5)

EXECUTIVE BOARD MEMBERS

Term of Office: 1999-2002

- OFFICIAL BALLOT -

There are five positions for members of the TASH Executive Board to be filled this year. Positions will be filled via ballot by dues-paying TASH members (one each) in accordance with the Association's By-Laws. The Executive Board member-elects will begin their terms at the Annual Board Meeting held in conjunction with the 1999 TASH Conference, December 8-11 in Chicago, Illinois.

Ballot Instructions:
You should vote for a total of FIVE nominees. Ballots containing more than five votes are invalid. Please mark your ballot in ink.

☐ **Jeff Bassin**	☐ **Ming-Gon John Lian**	☐ **Barbara Ransom**
☐ **Wanda Blanchett**	☐ **Tia Nelis**	☐ **Michael Remus**
☐ **Kathy Boundy**	☐ **Liz Obermayer**	☐ **Colleen Thoma**
☐ **Bob Kafka**		

For information about the candidates, please refer to pages 21-24 of this issue of the TASH *Newsletter*.

Mailing Instructions:
Ballots can be returned using this postage-free mailer, or originals of the ballot can be sent in an envelope. If you elect to use an envelope, please be sure the word BALLOT is printed on the front. If you use an envelope, please do not place anything other than your ballot inside; your envelope will not be opened until the counting of the ballots.

VERY IMPORTANT:
ONLY AN ORIGINAL BALLOT WILL BE CONSIDERED VALID.
PHOTO COPIES OR FAXES WILL NOT BE ACCEPTED.

Ballots must be received at the TASH Central Office by
OCTOBER 15, 1999

Mail your completed ballot to:
TASH, 29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204
Attn: Ballot

tape your completed Ballot

1999 TASH Executive Board Election B A L L O T Due in Baltimore on October 15, 1999!

FOLD BALLOT HERE

BUSINESS REPLY MAIL
FIRST-CLASS MAIL PERMIT NO. 1896 BALTIMORE MD

POSTAGE WILL BE PAID BY ADDRESSEE

TASH
29 W. SUSQUEHANNA AVE., STE. 210
BALTIMORE, MD 21204-9434

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

1999 Calendar of TASH Chapter and Member-Sponsored Conferences

SEPTEMBER

Promising Practices From Birth to . . .
Working Conference on Advocacy (System and Individual), Inclusive Education and Work
September 21-23
Crowne Plaza, Springfield, Illinois
Contact: Lynda Atherton
Phone: 815-758-2798
E-mail: llatherton@aol.com

National Spinal Cord Injury Association
Annual Meeting and Education Conference
September 26-29
Washington, D.C. Marriott at Metro Center
Contact: Denise Marshall
Phone: 410-828-8274, ext. 103

OCTOBER

8th Annual St. Amant Centre Conference "20th Century Trends, 21st Century Services?"
October 7 and 8
CanadInn, Winnipeg, Manitoba
Contact: Colette Choquette
Phone: 204-256-4301, ext. 298

DECEMBER

Annual TASH International Conference
"TASH 2000 - Our Turn Now"
December 8-11
Chicago Hilton and Towers
Contact: Kelly Nelson
Phone: 410-828-8274, ext. 105 or 1-800-482-8274, ext. 105
E-mail: knelson@tash.org

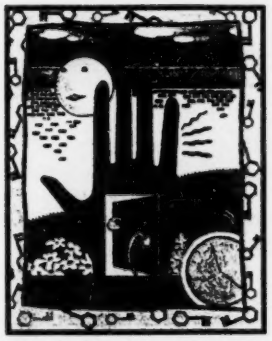
Do you have an upcoming TASH chapter meeting or member-sponsored conference that you would like to announce in the Newsletter? Send notice of the conference to Denise Marshall at dmarsh@tash.org at least 6 weeks before the event date. We will make every effort to include the event in the meetings calendar.

TEACHERS:
Children with Significant Disabilities

Public schools on beautiful Oregon coast have immediate openings for innovative, collaborative teachers with licensure and education/ experience with students with significant disabilities.

Prefer skills in augmentative/alternative communication, behavioral analysis including communicative functions, positive behavior intervention, supports for inclusion, functional assessment/instruction, curricular modification, transdisciplinary service delivery.

South Coast ESD
1350 Teakwood
Coos Bay, OR 97420
Attn: Sharon or Catherine
(541) 269-4520



"TASH 2000: Our Turn Now"

Chicago Hilton and Towers ◆ December 8-11
720 South Michigan Avenue
Chicago, Illinois 60605
312-922-4400 or 1-800-HILTONS
TASH Rates: $146.00 Single; $171.00 Double/Triple

Tentative Conference Agenda

Tuesday, December 7, 1999

8:00 PM - 10:00 PM	TASH Conference Registration

Pre-Conference Activities
Wednesday, December 8, 1999

7:30 AM - 8:45 AM	TASH Tech Registration
9:30 AM - 4:30 PM	Club TASH Day Care/Youth Activities
9:00 AM - 4:00 PM	TASH Tech Workshops
9:00 AM - 4:00 PM	TASH Development and Leadership Training
2:00 PM - 8:00 PM	TASH Conference Registration
4:30 PM - 5:00 PM	Welcome to TASH
5:00 PM - 7:00 PM	Opening Reception in the TASH Exhibit Hall

Thursday, December 9, 1999

7:30 AM - 1:00 PM	TASH Conference Registration
7:30 AM - 9:00 AM	TASH Exhibit Hall Open
8:30 AM - 5:45 PM	Club TASH Day Care/Youth Activities
8:30 AM - 10:00 AM	General Session
10:15 AM - 5:30 PM	Conference Sessions and Poster Presentations
11:00 AM - 6:00 PM	TASH Exhibit Hall Open
5:30 PM - 7:00 PM	Reception

Friday, December 10, 1999

7:30 AM - 11:00 AM	TASH Conference Registration
7:30 AM - 10:30 AM	TASH Exhibit Hall Open
8:30 AM - 5:45 PM	Club TASH Day Care/Youth Activities
8:00 AM - 10:15 AM	Conference Sessions and Poster Presentations
10:30 AM - 12:00 PM	General Session
12:15 PM - 4:45 PM	Conference Sessions and Poster Presentations
1:00 PM - 7:00 PM	TASH Exhibit Hall Open
5:30 PM - 7:00 PM	Reception
6:30 PM - 8:00 PM	TASH Open Forum and Business Meeting

Saturday, December 11, 1999

7:30 AM - 9:00 AM	TASH Conference Registration
7:30 AM - 12:00 PM	TASH Exhibit Hall Open
8:30 AM - 1:00 PM	Club TASH Day Care/Youth Activities
8:00 AM - 12:45 PM	Conference Sessions

1999 TASH KEYNOTE SPEAKERS

THURSDAY, DECEMBER 9, 1999

Rich Villa
As the President of Bayridge Consortium, Rich provides training and consultation in areas such as collaborative teaming, creative solutions, systems change, and inclusion. He also gives technical assistance to school districts, departments of education, and advocacy groups across the country and around the globe.

Diane Coleman
Diane has served on the governing boards of national, state and local disability-related organizations and policy-related committees, has authored numerous articles on disability-related topics and spoken extensively on topics pertaining to disability rights and health care issues. Diane has worked as an organizer for ADAPT and is founder of Not Dead Yet, a national grassroots disability rights organization.

Kyle Glosier
Kyle is a middle-school student and self advocate who uses augmentative communication. Having spoken at conferences and rallies since he was a young child, Kyle is now an experienced national and international speaker. Kyle is also an active member of ADAPT.

Jeff Moyer
Jeff is an internationally known disability advocate, songwriter, performer, author and leader whose work on the cutting edge of the disability rights movement has spanned over 25 years. Jeff's work challenges, uplifts and unites communities through recognizing the essential contributions of individuals, families and all members of the teams that advocate, support and educate.

FRIDAY, DECEMBER 10, 1999

Anne Donnellan
Anne is a Professor in the School of Education at the University of Wisconsin, Madison. Her keynote address, titled "Absence of Evidence - Not Evidence of Absence," will discuss how 19th century social biases and 20th century testing continue to condemn people with mental retardation, autism, and other disabilities to second class citizenship. Ann will inspire us to lead special education, rehabilitation and human services into the next millennium with creative new approaches to understanding and serving people who have been labeled.

Rosangela Berman-Bieler
Founder of the Independent Living Movement in Brazil, Rosangela is also the founder and current president of the Inter-American Institute on Disability (IID). Through her work with IID, Rosangela works to promote cooperation for the development and empowerment of people with disabilities in the Inter-American region, as well as Spanish and Portuguese speaking countries of Europe and Africa. Rosangela has been a quadriplegic since an automobile accident in 1976, and uses a wheelchair. Her keynote address will focus on the concept of "inclusion" as a new paradigm for the millenium and on the importance of international cooperation regarding disability issues worldwide.

TASH Conference Registration

"TASH 2000: Our Turn Now"

Chicago Hilton and Towers
December 8–11, 1999

Mail form to: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore MD 21204 *or*
Fax form to: TASH, (410) 828-6706
Questions? Call: 1-800-482-TASH (8274)
Email: registration@tash.org
TDD (410) 828-1306
This form can also be found on our website www.tash.org

TASH Office Use Only
Org _____
Cust _____
Reg _____
Rec _____
Init _____

Agency / Organization / School Information: (If applicable)

Name of Agency/Org/School: _____
❑ This organization is a current TASH Member # _____
Contact Person: _____
Address: _____
_____
City / State: _____ Zip/Postal Code: _____ Country: _____
Is this address the billing address? ❑ Yes ❑ No If no — indicate billing address and contact person with phone # here:

Conference Attendee: *(Please use a separate form for each person)*

First Name: _____ Last Name: _____
❑ I am a current TASH Member # _____ Preferred Badge Name: _____
Mailing Address _____
(if different from above) _____
City / State: _____ Zip/Postal Code: _____ Country _____
This address is ❑ home ❑ work ❑ school ❑ other _____ Please send my confirmation via ❑ email ❑ fax ❑ mail
Work Phone: _____ Home Phone: _____
Fax: _____ E mail: _____

TASH MEMBERSHIP:

❑ I am renewing my membership now Mem. #_____
❑ I am becoming a member now
If you are joining with 3 or more people from the same agency/organization/school take $20 off each person's applicable rate (must be in the same envelope)!

New And Renewing Members please select membership type (and add rate on other side) →

	International & Chapter	International Only	*Chapter Only
Individual	$103	$88	$33
Reduced Fee (circle one) Self-advocate/Parent/Student	$60	$45	$20
Family	$156	$136	$66
Organizational	$230	$200	$70
Lifetime	$1000	N/A	N/A

Attributes *(please circle all that apply)*

1. Administrator/Adult Services
2. Administrator/Education
3. Administrator/Other
4. Adult Service Provider/Staff
5. Advocate/Friend
6. Behavioral Specialist
7. Case Manager
8. Early Childhood Services
9. Educator/Teacher (K-12)
10. Government Personnel
11. Legal Services Provider
12. OT/PT
13. Parent/Family Member
14. Personal Assistant
15. Professional/Public Policy Advocate
16. Professor/Instructor (College/University)
17. Psychologist
18. Regular Education Teacher/Admin
19. Related Service Provider
20. Self-Advocate
21. Social Worker
22. Speech/Language Pathologist
23. Special Education Teacher
24. Support Specialist
25. Staff Development/Trainer
26. Student (College/University) List ID: _____
27. Supported Employment
28. Other _____

Accessibility and Additional Information Requests

❑ Sign Language Interpreter *Please indicate dates and times needed:* _____
❑ Please list any accessibility/ ADA accommodation needs: _____
Please note: information about accessibility at the hotel and surrounding vicinity will be available at the information desk on-site)
❑ Child Care/Youth Activities (Note: you must fill out an application in advance to register. Space is limited)
❑ Roommate Referral Program
❑ I would like a mentor to help me get acquainted with the TASH Conference while I am on-site
❑ I have been at the TASH Conference before and would agree to be a mentor to help others while on-site

* Chapter Only Membership does not qualify for reduced conference registration rates.

1999 TASH Conference Registration Payment Information

(Includes Opening Reception on 12/8/99 and Conference Activities 12/9–12/11/99)

TASH International Members:		
❑	Individual	$219
❑	Student	$169
❑	Parent (non-professional)	$ 49
❑	Self Advocate	$ 49
❑	One Day Only ❑ Thurs ❑ Fri ❑ Sat	$119
TASH Chapter only or Non-Members:		
❑	Individual	$329
❑	Student	$249
❑	Parent (non-professional)	$ 79
❑	Self Advocate	$ 79
❑	One Day Only ❑ Thurs ❑ Fri ❑ Sat	$169

NEW This Year — selected sessions will be audio-taped! Receive one free selection with your registration.

Enter Applicable Registration → $ _____

Discounts: (only one discount can be applied)

❑ Earlybird Registrations (Must be sent with payment by September 24th)	Subtract $20	
❑ Groups of 5 or more registering for full conference (all registrations must be received in the same envelope)	Subtract $20 per registrant	
❑ A direct support staff person registering with a self-advocate	Subtract $50 from the staff person's registration	
❑ Two or more members of the same school team registering together (ie: a special educator and a regular educator, or a regular educator and a paraeducator)	Subtract $50 per registrant	
	Enter Applicable Discount Here →	$ -( )

After November 12, 1999 registrations will be on-site only and a $40.00 late fee must be added. To ensure that your registration process goes smoothly and to save money we encourage you to register early. If you register on-site you must bring this form and payment or authorized PO with you at time of registration.

Enter Late Fee Here → $ _____

Enter Total Conference Registration From Above Boxes Here → $ _____

New This Year – I would like to order the 1999 TASH Conference Yearbook *(available in June, 2000) Order with your registration and save $10.00* ~~**$35.00**~~ **$25.00 →** $ _____

TASH Tech Pre-conference Workshops (Wednesday, December 8, 1999)

1st Choice: TASH Tech Session # _____
2nd Choice: TASH Tech Session # _____

PLEASE BE SURE TO SPECIFY YOUR CHOICES! (see page # 4)

❑ TASH Member	$65.00	
❑ Non-Member	$85.00	
❑ Self Advocate / Parent (Non-Professional)	$40.00	**Enter TASH Tech Fee Here →** $ _____
❑ TASH/NADD Symposium	$85.00	**Enter Symposium Fee Here →** $ _____

TASH Membership Dues from Page 5 $ _____

Less $20.00 for three or more joining as TASH Members from same Org/Agency/School $ -( )

Enter Total Membership Cost Here → $ _____

Additional donation to support a self advocate to attend the conference
❑ $5 ❑ $10 ❑ $20 ❑ Other $ _____

(add all applicable costs) **TOTAL AMOUNT ENCLOSED:** $ _____

Payment Terms: Registration will not be accepted without payment by check, official purchase order, or credit card authorization. Please note that payment must be in U.S. Funds only. A $25.00 processing fee will be added to all cancellations, or for purchase orders not paid prior to the conference. **No refunds will be given for cancellations after November 12, 1999.** $25.00 fee for returned checks or unauthorized charges.

❑ Check Enclosed ❑ Purchase Order / State Voucher no. _____

❑ Visa ❑ MasterCard ❑ Discover Name on Card: _____

Card Number: _____ Exp. Date: _____ Signature: _____

BEST COPY AVAILABLE

TASH TECH and Preconference Activities

TASH Preconference Workshops and the symposium (co-sponsored by NADD) are full day, in-depth sessions held on Wednesday, December 8, 1999. Registration is in addition to the full conference. Be sure to arrive early to participate in one of these dynamic and informative sessions and join us for the opening conference reception from 5:00–7:00 pm!

T-1 Expanding & Deepening Relationships between Community Members & Adults with Developmental Disabilities
Angela Novak Amado
Many agencies have begun working on building friendships between adults with disabilities and community members. This session will be for staff who have already initiated bridge-building efforts to: 1) share their experiences with others, 2) find avenues for going beyond barriers, and 3) discover ideas for expanding and deepening existing relationships.

T-2 Creating Field-Based Networks to Meet the Personnel Needs of Students with Severe Disabilities and Deaf-Blindness
Susan Bashinski, Margy Hornback, Donna Wickham, Gwen Beegle, Lynette Lacy
Kansas has implemented an innovative approach to providing exemplary education to students with severe disabilities in inclusive programs. The practices of this validated approach will describe an ongoing professional development model relying on excellent practicing teachers who consult with teacher teams around the state.

T-3 Tools for Working: SSI Work Incentives & Transition Age Youth
Sheila Fesko, John Butterworth, Vicki Brooke, Ellie Emanuel, Helena Hoas, William Halloran
Representatives from the Work Incentives Transition Network will provide participants with content material on the SSI program, the impact of working on SSI benefits, creative use of the work incentives to advance career goals and self-determination, and the role of schools in addressing SSI needs.

T-4 Creating and Maintaining Inclusive Learning Communities: Community, Curriculum and Teacher Inquiry
Mary Fisher, Mara Sapon-Shevin, Lucille Zeph
This interactive workshop will address the three essential components of inclusive learning communities: 1) community building, 2) effective current and emerging practices in general education curriculum and instruction, and 3) reflective practice and teacher inquiry. The presenters intend to create a community of learners that will result in an exciting and effective learning experience — helping to bridge the gap between research (or the ideal) and practice.

T-5 Functional-Contextual Assessment & Portfolio Design
Mary Fitzgerald, Susan Catlett, Eve Cugini, Charlene Comstock-Galagan, Sharon Lynch
This highly interactive session will explore the process of functional-contextual assessment as it relates to evaluation procedures under IDEA 1997. The process emphasizes a team approach, (including parents), careful examination of current data and data collection strategies that yield meaningful information which links to appropriate IEPs. Participants will also learn about and interact with student portfolios designed by parents.

T-6 Emergency Management
Gary Lavigna
When punishment is no longer used to manage behavior, people ask, "What do we do when the behavior occurs?" "What do we do in a crisis?" This seminar will provide an overview of emergency management and reactive strategies that might be used as part of a complete support plan.

T-7 Whole Brain Learning: Inclusive Academics, Music & Games
Robin Smith, Kate Farrar
This highly participatory workshop will emphasize use of multiple intelligences to enhance academic and social engagement and establish a competence-oriented learning community. Participants will experience music, body sculpture, and kinesthetic games to support academics in inclusive classrooms along with other approaches that support "whole brain" or "brain compatible" learning. We will discuss applications at all grade levels and particular students that the participants may have in mind.

T-8 Developing Augmentative Communication Systems to Support Participation in General Education Classrooms
Rae Sonnenmeier, Michael McSheehan
Developing an augmentative communication system within an inclusive educational setting requires a thoughtful process to ensure that a stabilized communication system is not a prerequisite to being included. The phases of developing such a system, including considering the features of technology, and selecting vocabulary to increase curricular and social participation in general classrooms will be presented. This session will include discussion, interactive problem solving, exploration of technology, and personal stories.

T-9 Including Students with Disabilities as Fully Participating Members of the High School Community
Carol Tashie, Mary Schuh, Jeff Strully
Why students with disabilities should spend their high school career with all peers and strategies for overcoming obstacles that cause students to spend time away from typical peers will be discussed. What students should be learning in classes, after-school, weekends, and the transition to jobs will be discussed.

T-10 Organizing for Disability Rights and Inclusion
Steve Taylor, Bonnie Shoultz and Others
This TASH Tech will examine a range of grassroots community organizing strategies that people with disabilities, family members, and advocates can use to promote the full participation of people with disabilities in community life. Topics to be discussed include: building coalitions with disability and non-disability groups, developing position statements, sponsoring public forums and other actions, working with the media, organizing petition drives and letter-writing campaigns, and other non-legal and non-legislative strategies. These topics will be explored through presentations, small group discussions, and exercises. Participants will also receive an information packet on organizing strategies.

T-11 The Behavior-Communication Link
Kim Davis, Susan Dixon
Behavior is often overlooked as a legitimate means of communication. This workshop will provide information to families and individuals who support people with disabilities to build an understanding of how different behaviors are communicative, to understand what their messages might be and how to begin to interpret those messages.

T-12 Civil Rights, Decision Making and Guardianship: Melding TASH Values with Best Practices
Dohn Hoyle, Kathleen Harris, Joel Welber, Sally Burton-Hoyle, Patricia Dudek, Mayer Shevin
With the establishment of guardianship for individuals with disabilities, their ability to make decisions about their own lives has frequently been taken away. This workshop will focus on a number of preferable alternatives to support all people at risk including individuals with the most significant decision making support needs. Discussion will include best practices in alternatives to legal guardianship, some recent court decisions, and philosophical debate surrounding self-determination and choice making for people who are at risk of losing their right to make their own decisions. This session is designed for long term advocates, family members, attorneys, case management agency staff, and all those who believe in the principles of freedom and self-determination.

T-13 IDEA: What Parents & Advocates Need to Know
Dixie Jordan
Join the co-director of the Families and Advocates Partnership for Education Program from PACER Center for a full day of training on IDEA following its 1997 reauthorization and newly released regulations. This workshop is organized around the six principles of IDEA '97 which are: a free and appropriate education, appropriate evaluation, IEP development, least restrictive environment, parent and student rights in decision-making, due process procedures. Also included is a special focus on new school discipline policies. This workshop is designed to help parents and advocates learn what they need to know to plan an effective program for their children and young adults with disabilities.

T-14 The Ethics of Touch
Dave Hingsburger
This full day workshop will explore the issue of providing intimate care to people with developmental disabilities. It will also examine the role of front line staff and their complex socio-therapeutic relationship with the people they serve. Participants will discuss how these staff members should define their job. Are they therapists? Friends? Family? Is it appropriate to meet the emotional/relationship needs of people with disabilities? What about touch? What is most appropriate? Hugs? Handshakes? Both? Neither? This session will address each of these questions. Also, participants will learn practical ways of respecting boundaries while providing intimate physical and emotional service. Issues ranging from appropriate ways to show affection to how to bath and toilet someone with significant disabilities will be addressed.

In addition to the TASH Techs that are being held on Wednesday, December 8th, TASH is holding the **3rd Annual Chapter Leadership Development Day** — An opportunity for chapter officers to share ideas, concerns and strategies. This day long event will feature formal presentations along with skill-building opportunities.

All current Chapter officers will receive invitations to this exciting day of planning and collaborating. If you are interested in starting a chapter and would like to participate in the 1999 Chapter Leadership Day on December 8th, call Nancy Weiss at 410-828-8274, ext. 101 or e-mail: nweiss@tash.org

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Special Symposium

Behavioral Supports: Individual Centered Interventions
William I. Gardner, Ph.D. and Dorothy M. Griffiths, Ph.D.

This symposium is for people supporting individuals with developmental disabilities and mental health concerns. The presenters will describe a range of medical, psychiatric, psychological, social and environmental features involved in the development and continuation of behavioral and emotional challenges that represent barriers to quality of life. Numerous case illustrations will be presented throughout to demonstrate use of multimodal (bio-social-social) functional case formulation process in devising individual centered interventions for these challenges. The Individual Centered Behavioral Interventions described in this presentation are designed to enhance the competencies of person supported rather than merely to reduce or eliminate emotional and behavioral challenges.

William I Gardner, Ph.D., a clinical psychologist, is on the faculty of the Rehabilitation Psychology Program at the University of Wisconsin-Madison. Dr. Gardner serves on the Board of Directors of NADD. He is a frequent presenter at national and international meetings and provides training and clinical consultations to programs serving person with significant mental health concerns. Dr. Gardner is the author of numerous articles and books.

Dorothy M. Griffiths, Ph.D. is on the faculty of Brock University, Ontario. Dr. Griffiths is President of the NADD Board of Directors. Her frequent training workshops and consultations throughout North American focus on supporting persons with challenging behavioral and emotional features. Dr. Griffiths has authored many articles and has co-authored books addressing challenging behaviors in persons with

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TASH NEWSLETTER

Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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Donna Gilles, *Chair of the Executive Committee*
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Jacqueline Thousand

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Is the above your ❑ work address ❑ home address ❑ other _____

Please Check Appropriate Categories (not more than three):

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( ) Administrator/Education
( ) Administrator/Other
( ) Adult Service Provider/Staff
( ) Behavior Specialist
( ) Case Manager
( ) Early Childhood Services
( ) Educator/Teacher
( ) Gov. Personnel (Federal, State, Local)
( ) Interested Individual/Advocate/Friend
( ) Legal Services Provider
( ) Occupational/Physical Therapist
( ) Parent/Family Member
( ) Personal Assistant
( ) Professional Public Policy Advocate
( ) Professor/Instructor (College/University)
( ) Psychologist
( ) Regular Education Teacher/Administrator
( ) Related Services Provider
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Special Education Teacher/Support Specialist
( ) Staff Development/Trainer
( ) Student (College/University)
( ) Supported Employment/Day Personnel
( ) Other

Moving? ***Please notify TASH of your new address.***

General Membership (individual)	$88
Agency/business/university/college/library/school (allows 3 conference attendees at the member rate)	$200
Self-Advocate, Parent, Full Time Student, Direct Careworker/Para professional/Personal Attendant (for whom payment of full fee would present a hardship)	$45
Family (group rate)	$136
Lifetime Member	$1000

Add $10 for postage costs for members in Canada and $25 for members outside the U.S. and Canada.

Funds must be submitted in U.S. dollars and checks must be drawn on a U.S. bank. Add a $20 processing fee if check is not drawn on a U.S. bank. If you would like to charge your membership, please fill in the necessary information:
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College/University _____

Student I.D. Number _____

Anticipated year of completion _____

( ) Include an additional $15 if you are applying for an individual membership or $30 if you are applying for an organizational membership and also want to become a member of your local chapter.

Please make check payable to: TASH
Address: 29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204
Telephone: 410/828-8274 Fax: 410/828-6706

TASH
29 West Susquehanna Avenue
Suite 210
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Phone: 410/828-8274,
FAX: 410/828-6706,
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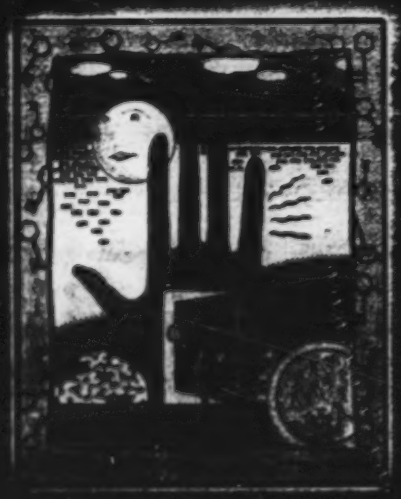
TASH

Newsletter

VOLUME 25 ISSUE NUMBER 9 SEPTEMBER 1999

"TASH 2000: Our Turn Now"

1999 TASH Conference



This is the tentative conference agenda as of 9/1/99 and is subject to change. The official conference program is distributed on-site.

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©ParaEducators: LifeLines in the Classroom

1999-2000
Trainer-of-Trainer
Sessions

Build in-district resources to ensure on-going paraeducator training by attending this 3-day workshop to become a ©LifeLines trainer.

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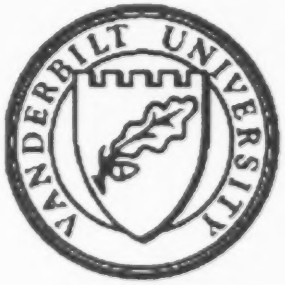
GRADUATE PROGRAMS IN SPECIAL EDUCATION

VANDERBILT UNIVERSITY PEABODY COLLEGE

This department is nationally ranked as one of the leading programs in special education. Master's degree programs include: Early Childhood Special Education, Behavior Disorders, Learning Disabilities, Severe Disabilities, Secondary Transition, and Visual Disabilities. The faculty are engaged in innovative research and development projects and support a rigorous, research oriented doctoral program. Doctoral program emphases include Behavioral Disorders and Transition, Learning Disabilities, Early Childhood Special Education, Visual Disabilities, and Severe Disabilities. Generous financial support packages are available.

Applications are accepted on a continuous basis. Please contact Lynda Wyatt (lynda.wyatt@vanderbilt.edu) Department of Special Education, Box 328, Peabody College of Vanderbilt University, Nashville, TN 37203; (615) 322-8195 or visit the Web site at **http://www.peabody.vanderbilt.edu** for additional information. Vanderbilt University has a strong commitment to diversity and actively seeks applications from minorities and individuals with disabilities.



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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Ste. 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 108 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

—

Building communities in which no one is segregated and everyone belongs;

—

Forging new alliances that embrace diversity;

—

Advocating for opportunities and rights;

—

Eradicating injustices and inequities;

—

Supporting research and disseminating knowledge and information;

—

Promoting inclusive education;

—

Supporting progressive legislation and litigation; and,

—

Promoting excellence in services.

From the Executive Director

BY NANCY WEISS

I have been a TASH member for a far greater number of years than I have served as a staff person to this wonderful organization. As a member, each year, I would await the conference edition of the *Newsletter* with anticipation. As soon as I received it I would dive in to see what topics were being covered, who was speaking, and which TASH Tech I would select for that year. Welcome to this year's Conference Edition!

TASH Conferences are never a disappointment. They are rich, engaging experiences that help each of us come away with renewed energy and excitement for the work that we do in building better lives for people with disabilities – whether we do that as self-advocates, family members, on behalf of individuals we support or as representatives of organizations, schools, universities or government agencies.

The theme for this year's conference is "TASH 2000 – Our Turn Now". The conference – the final disability conference of this millennium—heralds the beginning of a new era. It is our turn now – our turn for equity, social justice, diversity and meaningful lives for all people with disabilities and their family members.

Whether you are a long-time participant or have never attended a TASH conference before, make plans now to be a part of this remarkable coming together of parents, self-advocates, professionals, researchers, professors and students – all of us tied together by a shared set of values and beliefs. There are few experiences more invigorating. Get charged up for the new millennium with the greatest number of sessions on the broadest range of topics that TASH has ever offered.

At last year's conference the convention center staff were amazed at how the halls emptied out when sessions started. TASH conference sessions are not your run-of-the-mill "listen-to-the-expert" type sessions. They are spirited opportunities for meaningful interaction on the topics that are most critical to the lives of people with disabilities today. TASH conferences are designed to provide multiple opportunities to get to know speakers and other participants. Here's *your* opportunity. Come to Chicago to meet people from across the street and across the world who have devoted their lives, as you have, to making the world a better place to be a person with a disability. See you there!

Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail dmarsh@tash.org
- **For questions about the 1999 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail knelson@tash.org
- **For questions about membership, conference registration or exhibiting call:** Rose Holsey, Director of Operations, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on governmental affairs or the TASH Website, call:** Dan Dotson, Acting Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail ddotson@tash.org
- **For information on marketing and promotions, permission and reprints, newsletter submissions or advertising, or publication sales, call:** Priscilla Newton, Director of Marketing and Communications, at (410) 828-TASH, Ext. 102, e-mail pnewton@tash.org
- **For information on the Journal (JASH), call:** Linda Barbara, Editor-in-Chief, at (610) 758-3271, e-mail: LMBL@lehigh.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette, in large print and in braille for people whose disabilities make this form preferable. Call (410) 828-8274 ext. 102 to request the recorded version. Requests for permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org

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"TASH 2000: Our Turn Now"

1999 TASH Conference

Chicago Hilton and Towers • December 8–11th

Chicago is our kind of town!

Make it your town too! Plan to join us for "TASH 2000: Our Turn Now" to be held at the Chicago Hilton and Towers. The TASH Conference is where the best of hearts and minds in the disability movement gather to provide and share cutting-edge information that inspires advocates, parents, and professionals alike to understand, support, and creatively move forward toward inclusive lives for all. Whether you are coming from around the world or across the street, this is the place to join over 2500 activists, advocates, educators, and leaders in the quest for full inclusion and participation for all people with disabilities — regardless of their level of disability or need for support.

What you'll find at the TASH Conference:

- Over 450 cutting-edge sessions on issues that directly affect the lives of people w/ disabilities and their families
- Practical strategies and information that you can put to use immediately
- Representatives of many of the leading disability-related manufacturers, publishers, and suppliers exhibiting in the TASH exhibit hall
- A collective spirit that energizes and renews everyone who attends the conference. TASH is known for our uncompromising stance and unrelenting action: insisting on full participation and community inclusion for all!

Look for sessions that span the spectrum of issues affecting people with disabilities and their families. Topic areas include:

- Advocacy
- Building Alliances and Coalitions
- Communication
- Community Living
- Creative and Performing Arts
- Criminal Justice
- Curriculum Adaptation
- Deaf Culture
- Dual Sensory Impairment
- Due Process
- Early Childhood
- Educational Reform
- Employment and Careers
- Family Issues
- Functional Assessment for Behavior Change
- Governmental Affairs
- Grassroots Organizing
- Guardianship
- High School Inclusive Education
- Higher Education
- Housing/Home of Your Own
- IDEA Monitoring and Enforcement
- IDEA '97 Regulations
- Impacting Legislation
- Inclusive Education Strategies
- Independent Living Centers, Councils, and Services
- Integrated Sports
- International Inclusive Education
- Internet and Disability
- Issues of Death and Dying
- Issues of World Peace & Social Change
- Leisure and Recreation
- Life Transitions & Changes in Supports for Aging Adults
- Managed Care
- Management Issues
- Mediation
- MiCASSA/Personal Assistance
- Multicultural Issues
- Paraprofessional Issues
- Personnel Preparation
- Positive Approaches to Behavior Change
- Qualitative & Quantitative Research
- Rehabilitation Act
- Related Services in Inclusive Education
- Self-Advocacy
- Self-Determination
- Sexuality, Romance, & Dating
- Special Health Care in Inclusive Settings
- Special Health Care Needs
- Spirituality
- Standards Based Reform and Assessment
- Students Who Severely Challenge Schools
- Systems Change at the Local Level
- Systems Change at the Policy Level
- Teacher Preparation
- Transition from School to Work
- Urban Education Issues

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Tentative Conference Agenda

Tuesday, December 7, 1999

8:00 AM – 10:00PM TASH Conference Registration

Wednesday, December 8, 1999

7:30 AM – 8:45 AM TASH Tech Registration
9:30 AM – 4:30 PM Club Tash Day Care/Youth Activities
9:00 AM – 4:00 PM TASH Techs And NADD Symposium
9:00 AM – 4:00 PM TASH Chapter Development And Leadership Training
2:00 PM – 8:00 PM TASH Conference Registration
4:30 PM – 5:00 PM Welcome To TASH
5:00 PM – 7:00 PM Opening Reception, in the TASH Exhibit Hall

Conference Activities
Thursday, December 9, 1999

7:30 AM – 1:00 PM TASH Conference Registration
7:30 AM – 9:00 AM TASH Exhibit Hall Open
8:30 AM – 5:45 PM Club TASH Day Care/ Youth Activities
8:30 AM – 10:00AM General Session
10:15AM – 5:30 PM Conference Sessions and Poster Presentations
11:00 AM – 6:00 PM TASH Exhibit Hall Open
5:30 PM – 7:00 PM Reception

Friday, December 10, 1999

7:30 AM – 11:00 AM TASH Conference Registration
7:30 AM – 10:30 AM TASH Exhibit Hall Open
8:30 AM – 5:45 PM Club TASH Day Care/Youth Activities
8:00 AM – 10:15 AM Conference Sessions And Poster Presentations
10:30AM – 12:00 PM General Session
12:15PM – 4:45 PM Conference Sessions And Poster Presentations
1:00 PM – 7:00 PM TASH Exhibit Hall Open
5:30 PM – 7:00 PM Reception

Saturday, December 11,1999

7:30 AM – 9:00 AM TASH Conference Registration
7:30 AM – 12:00 PM TASH Exhibit Hall Open
8:30 AM – 1:00 PM Club TASH Day Care/Youth Activities
8:00 AM – 12:45 PM Conference Sessions

This years TASH Conference logo (on the front cover) features one painting from a trilogy created by the staff of Howard Community Services, a division of the Howard Center for Human Services, in partnership with Vermont artist Suzanne LeGault. Howard Community Services, located in Burlington, Vermont, provides a comprehensive array of supports and services to individuals with developmental disabilities and their families.

1999 TASH Keynote Speakers

Thursday, December 9, 1999

Richard Villa

Rich has been a general and special education teacher as well as an administrator in one of the nations first totally inclusive school districts. As the President of Bayridge Consortium, he provides training and consultation in areas such as collaborative teaming, creative solution-finding, systems change, and inclusion. Rich provides technical assistance to school districts, departments of education and advocacy groups across the country and around the globe. Rich says: "The future can be a terrible or wonderful thing, a seed bearing two vines — inclusion or exclusion." Rich's keynote will explore possible futures of education and will issue a call for action.

Diane Coleman

Diane is a person with significant disabilities who obtained her law degree and Masters in Business Administration from the University of California in 1981. She has served on governing boards of numerous national, state, and local disability related organizations and policy related committees, has authored numerous articles on disability-related topics and spoken extensively on topics pertaining to disability rights and health care issues. Diane has worked as an organizer for ADAPT and founded Not Dead Yet, a national grassroots disability rights organization leading the disability community's opposition to the legislation of assisted suicide and euthanasia. Her keynote will both educate and update advocates on this controversial issue.

Kyle Glosier

Kyle is an up and coming star in the disability rights movement. This middle school student from Pennsylvania is an experienced spokesperson for people with disabilities. He has spoken at many conferences and rallies since he was a young child. In his keynote address, Kyle will share his experiences as an advocate for himself and others, and his perspectives on the future of inclusive communities. Kyle embodies the theme of this years conference — Our Turn Now — and will continue to develop into a strong leader as he pushes for an inclusive society.

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1999 TASH Keynote Speakers Continued

Jeff Moyer

Jeff is an internationally known disability advocate, songwriter, performer, author, and leader whose work on the cutting edge of the Disability Rights Movement has spanned over 25 years. His recorded albums of music, activity book, musical and song programs and materials for augmentative communication aid users and teach the vital lesson that disability is a normal aspect of human diversity. Jeff's work challenges, uplifts and unites communities through recognizing the essential contributions of individuals, families and all members of the teams that advocate, support and educate. His keynote will share the music that has documented our history and lifts high the dignity and wholeness of all people.

Friday, December 10, 1999

Anne Donnellan

Anne is a Professor in the School of Education at the University of Wisconsin, Madison. Her keynote address, titled, "Absence of Evidence – Not Evidence of Absence" will discuss how nineteenth century social biases and twentieth century testing continue to condemn people with mental retardation, autism, and other disabilities to second class citizenship. Never one to shrink away from confronting conventional wisdom, Anne will inspire us to lead special education, rehabilitation and human services into the next millennium with creative new approaches to understanding and serving people who have been labeled.

Rosangela Berman-Bieler

Rosangela is a Brazilian journalist, publisher and disability rights advocate as well as a professional meeting planner. Founder of the Independent Living Movement in Brazil, she is also the founder and current president of the Inter-American Institute on Disability (IID). Through her work with IID, Rosangela works to promote cooperation for the development and empowerment of people with disabilities in the Inter-American region, as well as Spanish and Portuguese speaking countries of Europe and Africa. Rosangela has been a quadriplegic since an automobile accident in 1976, and uses a wheelchair. Her keynote address will focus on the concept of "inclusion" as a new paradigm for the millenium and on the importance of international cooperation regarding disability issues worldwide.

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General Information

Headquarter Hotel and Conference Location
Chicago Hilton and Towers
720 South Michigan Avenue
Chicago, Illinois 60605
Telephone: 312-922-4400
Fax 312-922-5240
Reservations 1-800-HILTONS

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1999 TASH Conference Rates

$144.00 Single
$169.00 Double
Current Chicago Taxes are 14.9%
Please call early to ensure space. Rooms are held until November 22, 1999. After that date reservations will be accepted based on availability. Please specify that you are calling regarding the TASH Conference.

Airports

O'Hare International Airport
773-686-2200
The Chicago Hilton and Towers is located 18 miles/45–90 minutes from the O'Hare Airport
Mid-Way Airport
773-838-0600
The Chicago Hilton and Towers is located approx. 12 miles/20–40 minutes from the Mid-Way Airport

Ground Transportation

Chicago Transit Authority
For information on the rapid transit trains and bus information, fares, or accessible routes please call 1-888-968-7282 or 312-836-7000

Continental Airport Express
312-454-7799 1-800-654-7871
Continental's Airport Express provides van rides from O'Hare every 5 minutes for $16.00 or $29.00 round trip. From Midway, the vans depart every
15–20 minutes and cost $10.50 one way and $19.00 roundtrip. For wheelchair accessible vans, please contact the service at least 24 hours in advance.

Taxi services offering fully accessible minivans and/or wheelchair accessible cabs:
Yellow Cab
312-829-4222 x2

Companies that service, sell and rent medical equipment, including wheelchairs, scooters and beds:
Metro Rehab Services 708-361-7060
Amigo Mobility 630-268-8670

Kozy Cycling (Wheelchair Tire Repair)
312-360-0020

Agencies that provide personal assistance services:
Help at Home 312-461-9000
Addus Health Care 312-663-4647

No Smoking/Accessible Environment Policy
For the comfort and health of all attendees, smoking is not permitted at any function. We also request that presenters and attendees refrain from using perfume/colognes during the conference sessions, exhibits, and receptions.

Visitor Information
Chicago Office of Tourism 312-744-2400

For general information about accessible services in and around Chicago or to
subscribe to their weekly faxed newsletter "Access Notes" please call
City of Chicago, Mayor's Office for People with Disabilities
Phone: 312-744-7050 TTY: 312-744-4964

Family Reunion

It's been 25 years of families meeting families at TASH and we want to celebrate! So pack your bags and come to Chicago for the 1999 TASH Conference and the Family Reunion. We welcome new attendees as well as those from past years. Stay for a few minutes or stay for the whole two 1/2 days. See you in the family gathering room! Check the program for location when you arrive!

It's time to renew old friendships and make new acquantances. Here's what will be part of the family gathering:

- Family Issues Presentations
- Create a Family Album – (bring pictures of your family please!)
- Fun Activities
- A place to relax
- Watch family videos (bring your favorite home video please!)
- Help us redefine "Family"
- Reunion door prizes and awards

For questions on the Family Reunion please contact Lynda Atherton by e-mail at llatherton@aol.com or by phone at 815-758-2798

CITY OF CHICAGO

Mayor's Office for People with Disabilities

City Hall, Room 1104
121 North LaSalle Street
Chicago, IL 60602
Phone: 312-744-7050
TTY: 312-744-4964
Web Site: www.ci.chi.il.us./Disabilities/

Dear Friends:

On behalf of Mayor Richard M. Daley and the Mayor's Office for People with Disabilities (MOPD), I look forward to meeting you in Chicago for "TASH 2000: Our Turn Now." MOPD is proud to sponsor this conference of international importance. We trust that your stay in our city will be both productive and enjoyable.

Since MOPD's creation in 1990, we have labored tirelessly to achieve our goal of making Chicago the most accessible city in the nation. You will find that our city's major tourist attractions, including the wonderfully revitalized Navy Pier and our world-class museums, are accessible to all - as are our best hotels and other accommodations.

It is Chicago's privilege and pleasure to host TASH members and supporters. Please count on MOPD as your local resource in assuring access to all that our city has to offer. Feel free to call us at 312-744-7050 (voice) or 312-744-4964 (TTY) when making your travel plans.

Lawrence J. Gorski, Director, Chicago Mayor's Office for People with Disabilities

Join Lawrence Gorski, Director of the Chicago Mayor's Office for People with Disabilities, on Friday, December 10 from 8:30-10:15AM in a discussion of the voting rights, political voice and election opportunities for people with disabilities during the presidential election year. Awakening the Sleeping Giant: The Power of Millennium. This session is part of the Governmental Affairs Strand.

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TASH TECH and Preconference Activities

TASH Preconference Workshops and the symposium (co-sponsored by NADD) are full day, in-depth sessions held on Wednesday, December 8, 1999. Registration is in addition to the full conference. Be sure to arrive early to participate in one of these dynamic and informative sessions; whether or not you can make it for a TASH Tech, plan to arrive in time to join us for the opening conference reception from 5:00–7:00 pm in the TASH Exhibit Hall!

T-1 Expanding & Deepening Relationships between Community Members & Adults with Developmental Disabilities

Angela Novak-Amado

Many agencies have begun working on building friendships between adults with disabilities and community members. This session will be for staff who have already initiated bridge-building efforts to: 1) share their experiences with others, 2) find avenues for going beyond barriers, and 3) discover ideas for expanding and deepening existing relationships.

T-2 Creating Field-Based Networks to Meet the Personnel Needs of Students with Severe Disabilities and Deaf-Blindness

Susan Bashinski, Margy Hornback, Donna Wickham, Gwen Beegle, Lynette Lacy

Kansas has implemented an innovative approach to providing exemplary education to students with severe disabilities in inclusive programs. The practices of this validated approach will describe an ongoing professional development model relying on excellent practicing teachers who consult with teacher teams around the state.

T-3 Tools for Working: SSI Work Incentives & Transition Age Youth

Sheila Fesko, John Butterworth, Vicki Brooke, Ellie Emanuel, Helena Hoas, William Halloran

Representatives from the Work Incentives Transition Network will provide participants with content material on the SSI program, the impact of working on SSI benefits, creative use of the work incentives to advance career goals and self-determination, and the role of schools in addressing SSI needs.

T-4 Creating and Maintaining Inclusive Learning Communities: Community, Curriculum, and Teacher Inquiry

Mary Fisher, Mara Sapon-Shevin, Lucille Zeph

This interactive workshop will address the three essential components of inclusive learning communities: 1) community building, 2) effective current and emerging practices in general education curriculum and instruction, and 3) reflective practice and teacher inquiry. The presenters intend to create a community of learners that will result in an exciting and effective learning experience — helping to bridge the gap between research (or the ideal) and practice.

T-5 Functional-Contextual Assessment & Portfolio Design

Mary Fitzgerald, Susan Catlett, Eve Cugini, Charlene Comstock-Galagan, Sharon Lynch

This highly interactive session will explore the process of functional-contextual assessment as it relates to evaluation procedures under IDEA 1997. The process emphasizes a team approach, (including parents), careful examination of current data, and data collection strategies that yield meaningful information which links to appropriate IEPs. Participants will also learn about and interact with student portfolios designed by parents.

T-6 Emergency Management

Gary Lavigna

When punishment is no longer used to manage behavior, people ask, "What do we do when the behavior occurs?" "What do we do in a crisis?" This seminar will provide an overview of emergency management and reactive strategies that might be used as part of a complete, proactive and positive support plan.

T-7 Whole Brain Learning: Inclusive Academics, Music & Games

Robin Smith, Kate Farrar

This highly participatory workshop will emphasize use of multiple intelligences to enhance academic and social engagement and establish a competence-oriented learning community. Participants will experience music, body sculpture, and kinesthetic games to support academics in inclusive classrooms along with other approaches that support "whole brain" or "brain compatible" learning. We will discuss applications at all grade levels and particular students that the participants may have in mind.

T-8 Developing Augmentative Communication Systems to Support Participation in General Education Classrooms

Rae Sonnenmeier, Michael McSheehan

Developing an augmentative communication system within an inclusive educational setting requires a thoughtful process to ensure that a stabilized communication system is not a prerequisite to being included. The phases of developing such a system, including considering the features of technology, and selecting vocabulary to increase curricular and social participation in general classrooms will be presented. This session will include discussion, interactive problem solving, exploration of technology, and personal stories.

T-9 Including Students with Disabilities as Fully Participating Members of the High School Community

Carol Tashie, Mary Schuh, Jeff Strully

Why students with disabilities should spend their high school career with all peers and strategies for overcoming obstacles that cause students to spend time away from typical peers will be discussed. What students should be learning in classes, after-school, weekends, and the transition to jobs will be featured in this session.

T-10 Organizing for Disability Rights and Inclusion

Steve Taylor, Bonnie Shoultz and Others

This TASH Tech will examine a range of grassroots community organizing strategies that people with disabilities, family members, and advocates can use to promote the full participation of people with disabilities in community life. Topics to be discussed include: building coalitions with disability and non-disability groups, developing position statements, sponsoring public forums and other actions, working with the media, organizing petition drives and letter-writing campaigns, and other non-legal and non-legislative strategies. These topics will be explored through presentations, small group discussions, and exercises. Participants will also receive an information packet on organizing strategies.

T-11 The Behavior/Communication Link

Kim Davis, Susan Dixon

Behavior is often overlooked as a legitimate means of communication. This workshop will provide information to families and individuals who support people with disabilities to build an understanding of how different behaviors are communicative, to understand what their messages might be and how to begin to interpret those messages.

T-12 Civil Rights, Decision Making and Guardianship: Melding TASH Values with Best Practices

Dohn Hoyle, Kathleen Harris, Joel Welber, Sally Burton-Hoyle, Patricia Dudek,

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TASH TECH and Pre-Conference Activities

Continued from page 8

Mayer Shevin
With the establishment of guardianship for individuals with disabilities, their ability to make decisions about their own lives has frequently been taken away. This workshop will focus on a number of preferable alternatives to support all people at risk including individuals with the most significant decision making support needs. Discussion will include best practices in alternatives to legal guardianship, some recent court decisions, and philosophical debate surrounding self-determination and choice making for people who are at risk of losing their right to make their own decisions. This session is designed for long term advocates, family members, attorneys, case management agency staff, and all those who believe in the principles of freedom and self-determination.

T-13 IDEA: What Parents & Advocates Need to Know

Dixie Jordan
Join the Co-director of the Families and Advocates Partnership for Education Program from PACER Center for a full day of training on IDEA following its 1997 reauthorization and newly released regulations. This workshop is organized around the six principles of IDEA '97 which are: a free and appropriate education, appropriate evaluation, IEP development, least restrictive environment, parent and student rights in decision-making, due process procedures. Also included is a special focus on new school discipline policies. This workshop is designed to help parents and advocates learn what they need to know to plan an effective program for their children and young adults with disabilities.

T-14 The Ethics of Touch

David Hingsburger
This full day workshop will explore the issue of providing intimate care to people with developmental disabilities. It will also examine the role of front line staff and their complex socio-therapeutic relationship with the people they serve. Participants will discuss how these staff members should define their job. Are they therapists? Friends? Family? Is it appropriate to meet the emotional/relationship needs of people with disabilities? What about touch? What is most appropriate? Hugs? Handshakes? Both? Neither? This session will address each of these questions. Also, participants will learn practical ways of respecting boundaries while providing intimate physical and emotional service. Issues ranging from appropriate ways to show affection to how to bath and toilet someone with significant disabilities will be addressed.

An Opportunity for Chapter Leaders to Network and Plan for the Future!

In addition to the TASH Techs that are being held on Wednesday, December 8th, TASH is holding the Annual Chapter Leadership Day – An opportunity for chapter officers and representatives to share ideas, concerns and strategies.

This event has been held on the Wednesday before the conference, in one form or another, for the past five years and has been critical in strengthening relationships between the International TASH Board, Central Office and Chapter Leaders. The day includes opportunities for skill building, informal sharing of ideas and planning for the future. The Chapter Leadership Day has helped new chapters to identify directions for themselves and has assisted established chapters to influence policy and direction within their states. Whether you represent a thriving, a newly established, or a struggling chapter, the 1999 Chapter Leadership Day is an event you won't want to miss!

All current Chapter officers will receive invitations to this exciting day of planning and collaboration. If you are interested in starting a chapter and would like to participate in the 1999 Chapter Leadership Day on December 8th, call Nancy Weiss at 410-828-8274, ext. 101 or e-mail: nweiss@tash.org

Special Symposium

CO-SPONSORED BY NADD

Behavioral Supports: Individual Centered Interventions
William I. Gardner, Ph.D. and Dorothy M. Griffiths, Ph.D.

This symposium is for people supporting individuals with developmental disabilities and mental health concerns. The presenters will describe a range of medical, psychiatric, psychological, social and environmental features involved in the development and continuation of behavioral and emotional challenges that represent barriers to quality of life. Numerous case illustrations will be presented throughout to demonstrate use of multimodal (bio-social-social) functional case formulation process in devising individual centered interventions for these challenges. The Individual Centered Behavioral Interventions described in this presentation are designed to enhance the competencies of person supported rather than merely to reduce or eliminate emotional and behavioral challenges.

William I. Gardner, Ph D., a clinical psychologist, is on the faculty of the Rehabilitation Psychology Program at the University of Wisconsin-Madison. Dr. Gardner serves on the Board of Directors of NADD. He is a frequent presenter at national and international meetings and provides training and clinical consultations to programs serving person with significant mental health concerns. Dr. Gardner is the author of numerous articles and books.

Dorothy M. Griffiths, Ph.D. is on the faculty of Brock University, Ontario, Canada. Dr. Griffiths is President of the NADD Board of Directors. Her frequent training workshops and consultations throughout North America focus on supporting persons with challenging behavioral and emotional features. Dr. Griffiths has authored many articles and has co-authored books addressing challenging behaviors in persons with disabilities.

1999 In-focus Strands

The TASH conference is an incredible melding of people, topics, and information. It is the place where cutting-edge dialogue on disability issues is taking place. To help streamline some of this cutting-edge information, TASH members have taken the lead in organizing a sequence of sessions on identified topic areas. A strand simply means that the sessions will take place in the same room, for a designated period of time. In addition to these focused strands, there are other sessions on these topic areas occurring throughout the conference. Feel free to attend an entire strand, or just selected sessions within a strand.

Successful Aging for Adults with Developmental Disabilities: State-of-the-Art Approaches to Support Later Life Transitions

Thursday

Strand Coordinator: Alan Factor

This strand presents state-of-the-art approaches to support the successful aging of adults with developmental disabilities and their families including: progressive models for dementia care, older women's health issues, promoting choices and options in the community, and supporting families in making future plans.

Advocacy

Thursday-Saturday

Strand Coordinator: Liz Obermayer

Join this lively strand for a series of presentations on advocacy and self-advocacy. Sessions by advocates and self-advocates focus on the skills needed to effect change at both the personal and policy levels. All the sessions within the strand provide opportunities for discussing ideas and sharing strategies for success.

Supporting Students with Autism Spectrum Disorders in Typical Classroom Settings

Friday

Strand Coordinators: Cathy Apfel and Rae Sonnenmeier

This strand will provide participants with the knowledge, skills, and strategies to effectively educate students with Autism Spectrum Disorders in typical classroom settings. Topics include: collaboration with families; enhancing communication and language skills; literacy; disigning activities to foster social interactions; sensorimotor issues, self-regulation strategies, and positive behavioral supports.

Community Living

Thursday-Saturday

Strand Coordinator: Joe Wykowski

This strand focuses on a variety of issues concerning living in the community including supports, relationships, employment, and conversion of group living situations to supported living.

Creative Arts

Friday

Strand Coordinator: Paula Neville

This strand focuses on the use of creative and performing arts to empower individuals through self-expression and to foster inclusive schools and communities.

The Criminal Justice System and Persons with Disabilities

Thursday and Friday

Strand Coordinators: Barbara Ransom and Lisa Sonneborn

Ten years after the ADA, persons with disabilities continue to be voiceless victims, witnesses and denied their constitutional protections as accused persons. This strand provides participants with practical information on how they can enhance the abilities of self-advocates to protect themselves, develop strategies to minimize unjust practices, and provide services and build partnerships with community organizations in order to address the unmet needs of these individuals.

New Models for Reaching Learners at a Distance

Thursday

Strand Coordinator: Fred Spooner

Four innovative approaches for reaching learners at a distance will be presented. The models include Web based or individual access, video conferencing, satellite, and two-way interactive TV.

Due Process

Thursday

Strand Coordinators: Gail McGregor and Judy Gran

Are you facing the daunting prospects of going through a due process hearing to get a good program for your child? Have you been asked by a parent to be an expert witness and you have no idea what that might involve? Do you want to hear from others who have been through this experience and find out strategies that worked for them? Sessions in this strand will address these issues and more. As an added support to families, a number of attorneys will be available in "consultation rooms" throughout the day of strand so that families can sign up for a time to meet with an attorney to receive legal advice about issues of concerns regarding their child's school program.

Early Childhood

Thursday and Friday

Strand Coordinator: Beth Brennan and Elizabeth Erwin

This two day strand will highlight critical issues and practices in creating inclusive early education and child care options for young children with severe disabilities and their families.

Employment and Transition

Thursday - Saturday

Strand Coordinator: Mike Callahan

This strand will highlight over 30 sessions covering hot issues in the employment and transition of people with significant disabilities. Topics will include natural supports, choice, conversion, individualized planning, and much, much, more!

Faith and Religion

Friday

Strand Coordinator: Kim Farrington

This strand focuses on the important role of religion in the lives of people with disabilities. Too often, faith and religious beliefs are ignored. Presenters in this strand will provide information about current research on the accessibility of faith communities. Videos offering practical strategies for making churches and congregations accessible will also be presented.

Family Gatherings

Thursday - Saturday

Strand Coordinator: Lynda Atherton

From birth through adulthood, the Family Strand includes many exciting sessions. Some of these are: early intervention, respite, brothers and sisters, assistive technology, becoming an involved parent, personal futures planning, a legislative forum, and a chance to meet and honor past TASH Board Members who can tell us what is happening now in their families. If you become tired,

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In-Focus Strands

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bored, or overwhelmed, join us in the Family Gathering Room to relax, laugh, have fun, meet other families, reunite with families, and/or network.

Governmental Affiars

Friday and Saturday

Strand Coordinators: Marcie Roth and Dan Dotson

Join this strand as it explores the critical governmental, public policy and grassroots organizing issues affecting people with disabilities and their advocates.

Guardianship: Melding TASH Values with Best Practices

Friday

Strand Coordinators: Dohn Hoyle and Maver Shevin

This strand includes sessions that discuss guardianship as the last civil rights frontier, exploration of strategies for best practices in alternatives to legal guardianship, issues related to wills and trusts and a crackerbarrel to engage in open discussion about other important issues related to guardianship.

Inclusive Education

Thursday

Strand Coordinator: Cheryl Jorgensen

Students with significant disabilities have been included in general education classes since the mid-1980's. To this day, however, there remains much confusion and difference of opinion about the definition of inclusion and more importantly, what it ought to look like in everyday practice. We have come to be suspicious of phrases like "partial inlcusion" and "inclusion program" because we have seen supposedly included students leaving the school in segregated groups for community-based instruction, sitting by themselves at lunch, being left behind on field trips, and sitting in the back of the classroom tethered to a teaching assistant working on an "alternate" curriculum. Surely this ISN'T inclusion, but then, what exactly IS inclusion and what strategies promote the values and outcomes that TASH members value?

International Inclusion

Thursday

Strand Coordinators: Anne Smith and Zuhy Saheed

This strand will explore dimensions of inclusion/exclusion around the world. It will be structured for interactive discussion. Following brief panel presentations, both presenters and participants will respond to focused discussion questions to identify emerging themes around the global inclusive movements as well as to highlight activities in various nations and regions across several continents. The day will end with some strategic networking and discussion about how TASH members can become more actively involved in international inclusive education efforts.

High School Inclusion: Making it Work for Everyone

Friday

Strand Coordinators: Carol Tashie, Mary Schuh, Jeff Strully, Doug Fisher and Cheryl Jorgensen

On the verge of the new millenium, many high school students with disabilities still spend their days in segregated classrooms, life skills programs, and separate community-based instruction. This all day interactive, free-flowing, and productive strand is designed for people interested in making high school inclusion a reality for all students. Participants will share new information, gain innovative strategies, and problem-solve common obstacles to achieving fully inclusive high schools. Join the strand coordinators, and many others, to learn, challenge, debate and work together to make high school inclusion a reality for all students.

What Will it Take? Standards and Assessment for All

Saturday

Strand Coordinators: Doug Fisher and Caren Sax

This strand focuses on standards and assessment, including the ways in which students with disabilities have participated and experienced success with these reform efforts.

Facilitating and Supporting Inclusion in Community Recreation Sports

Thursday

Strand Coordinator: Cindy Burkhour

Community recreation and sports opportunities are for everyone! Come find out how to access all the fun stuff to do in your community. Learn how inclusion in recreation happens, what supports are available, how supports and services are financed, what recreation providers can do to welcome and support participation by people with disabilities and what you can do to make it happen in your neighborhood.

Multicultural Issues

Thursday

Strand Coordinator: Lynda Baumgardner

What a colorful and diverse world we have! With the events of this year, it is important that we nurture, each day, the beauty of everyone's differences. Be it color, culture, or ability. This strand will explore the successes and challenges of creating culturally competent family supports, educational programs, conferences and assistive technology.

Paraeducator Issues and Practices

Thursday

Strand Coordinator: Michael Giangreco

This strand addresses paraeducator issues and practices ranging from national standards to school and classroom practices.

Personnel Preparation: Critical Issues

Thursday

Strand Coordinator: June Downing

This strand will address issues in personnel preparation for school and community settings. Promising new strategies will be covered and questions raised regarding best approaches to adopt.

Positive Approaches/Positive Behavior Support

Thursday - Saturday

Strand Coordinators: Tim Knoster and Rob O'Neill

This strand will highlight practical application and research on positive approaches to supporting individuals with histories of problem behavior. In particular, this strand will highlight ways to expand findings and horizons in research, and translation of research into practice, across home, school, and community settings.

Professional Development: More Powerful Teaching

Friday and Saturday

Strand Coordinator: Janice Payne

With the authorization of IDEA, there is tremendous emphasis on training for staff. Professional development is seen as the key to successful school change and restructuring, improved learning outcomes for all students, and access to general education

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In-Focus Strands

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for students with all learning styles and disabilities. But... what models of professional development are the most successful? What are the characteristics of effective professional development? How can we train and retrain the best and the brightest to teach all our nation's children and youth? These are some of the questions to be addressed by this strand.

Self-Determination

Thursday - Saturday
Strand Coordinators: Hank Bersani and Liz Obermayer
This strand focuses on promoting self determination and choice in all areas of life and across the life span.

Boldly Addressing Issues of Sexuality in the New Millennium

Thursday
Strand Coordinators: Wanda Blanchett and Ann Heler
Sexuality and sexual expression are natural and important aspects of each of our lives. Accordingly, these sensitive and critical issues require thoughtful and individualized attention. Individuals also need support and information to act upon their choices and interests. This strand will highlight sessions that address issues related to this critical topic.

Children and Youth with Special Health Care Needs

Friday
Strand Coordinator: Donna Lehr
This strand focuses on children and youth with special health care needs. It features sessions on family supports, educational considerations, and medical interventions.

Spirituality Towards Justice and Equity

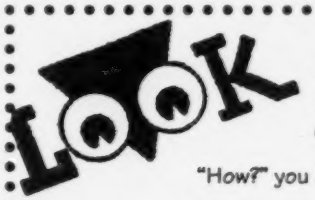
Thursday - Saturday
Strand Coordinators: Maureen Keyes and Madeline Hafner
As we strengthen our voices to take "our turn", sessions within the spirituality strand provide multiple perspectives on a variety of topics including futures planning, friendship, and teaching strategies.

Students Who Severely Challenge Schools But Who Do Not have Severe Disabilities

Friday
Strand Coordinator: Linda Rammler
The IDEA requires functional behavioral analyses for student with challenging behaviors,yet there are a substantial number of students with "mild" disabilities whose behaviors are viewed as voluntary. This strand will address the needs of these youngsters, their families, and their schools for technologies and supports that enable them, too, to lead inclusive and meaningful lives.

Urban Education

Thursday - Saturday
Strand Coordinators: Mark Doyle, Anne Smith, Lou Brown and Alison Ford
Not long ago, the idea of educating and supporting children with disabilities in inclusive urban settings was perceived as an overwhelming challenge. This strand features sessions from urban school districts around the country that have overcome many of the perceived barriers to urban education. Join them as they reveal that urban education can be a fun, exciting, golden opportunity for innovation. This strand promises to take participants beyond "talk"; participants will leave with some strategies to solve problems, to overcome barriers and to make the changes that are necessary in providing quality education for children with disabilities in complex urban settings.



how easy it is to get FREE registration to this year's information-packed TASH Annual Conference in Chicago!

"How?" you inquire excitedly. By volunteering, of course!

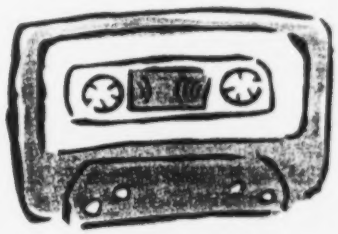
If you would like to attend the conference and save on registration fees, this is the deal for you! As a volunteer, you donate a minimum of 10 hours of service during the conference in exchange for complimentary registration to attend conference sessions during your non-volunteer periods.

Whether you've participated as a volunteer before, or would like to do so for the first time, **your services are urgently needed as a Conference Volunteer!**

If you are interested, please contact
Priscilla Newton at 1-800-482-8274, ext. 102
or e-mail <pnewton@tash.org>

New This Year!

Due to popular demand, select sessions will be audio-taped this year! Sessions that will be taped will be marked in the conference program. Each registrant will receive one tape complimentary with registration. Take your free tape coupon (given at conference registration) to the Creative Seminars Recording and Reproduction Booth in the Exhibit Hall and select your tape. While you are there, purchase additional tapes of your choice!



Thursday, December 9, 1999 10:15 AM - 11:15 AM

Strategies for Developing Policies & Systems to Improve Paraeducator Performance
Interest Area: Paraeducator Strand
Anna Lou Pickett

Steven's Story: Overcoming The Barriers to High School Inclusion
Interest Area: High School Inclusive Education
Ann McKee, Susan Hamre-Nietupski

Slidin' into Home: Supporting Self-Determination through Personal Support Agents
Interest Area: Self-Determination Strand
Phil Ferguson, Dianne Ferguson, Rick Blumberg

Developing and Maintaining Inclusive Employment & Activities for Everyone
Interest Area: Employment Strand
Gail Fricke, Karen Brineger-Price, Scott Baird

Teaching Secondary Teachers To Work with Students with Disabilities
Interest Area: Higher Education
Steven Lyon

Shaping a New Direction for Parents & Professionals During Transition
Interest Area: Transition Strand
Bud Cooney, Christi Hendrickson, Michele Dimon-Borowski

Project Aspire - Supporting Parents who Experience Cognitive Delays
Interest Area: Family
Kathy Ballard, Cathy Schvetter, Chris Sadenwater, Desiree Tilton, Peggy Terhune, Roxanna Soots, Sandy Taylor

Meaningful Inclusion of Children with Severe Disabilities in Play-Based Settings
Interest Area: Early Childhood Strand
Mary Frances Hanline, L. Penny Rosemblum

Positive Behavior Supports and Autism
Interest Area: Positive Approaches
Michael McSheehan, Rae Sonnenmeier

Creating School Change: Models of Team Problem Solving
Interest Area: Inclusive Education
Donna Wickham, Carole Gothelf, Jerry Petroff, Kathleen Gee, Lillian McCuen, Marguerite Hornback

The Disability Action Hall - A Political Space for People with Disabilities and their Allies
Interest Area: Self-Determination
Debbie Reid, Ryan Geake

A Journey to Independent Typing: Practice, Practice, Practice
Interest Area: Assistive Technology
Paula Kluth, Franklin Wilson, Pat Wilson

Generic or Specialized Special Education: What Are We Doing?
Interest Area: Personnel Preparation Strand
June Downing, Joanne Eichinger

An Elementary Teacher Educator in a Special Education World
Interest Area: Higher Education
Pennie Olson

Open Inquiry: A Post-Positivist Interpretation of Facilitative Communication
Interest Area: Research
Linda Ware, Lisa Cartwright

Getting the Process Together
Interest Area: Advocacy
Roy Brown

Team Training for Positive Behavioral Support: Individual State & Community Levels
Interest Area: Positive Approaches Strand
Jacki Anderson, Meme Nieneman, Richard Albin

Statewide Technical Assistance to Build Capacity in Schools
Interest Area: Inclusive Education
Ruth Henning, Kathryn Cox

What About Me?: Creating Safe Educational Environments for Nonheterosexual Students
Interest Area: Sexuality Strand
Wanda Blanchett, Pamela Wolfe

The Essence of Inclusion
Interest Area: Inclusive Education Strand
Jeff Strully

Recreation & Sports: What are your rights to access and your responsibilities as Participants
Interest Area: Leisure & Recreation Strand
Cynthia Burkhour

One Eighty One
Interest Area: Spirituality Strand
Tom Bauer

Thursday, December 9, 1999 10:15 AM - 12:30 PM

Home Ownership Strategies: A National Perspective on Assisting People to Purchase a Home
Interest Area: Community Living Strand
Joe Wykowski, Steve Allen

The Work Opportunities Project of the Chicago Public Schools
Interest Area: Urban Strand
Lou Brown, Deloras Freeman

The New Evolution of Support Circles: In and Out of the Classroom
Interest Area: Inclusive Education
Patrick Schwarz, Cindi Birse-Swanson, Kim Booth, Nancy E. Brown, Sharon Constabile

Providing Transitional Psychosocial Rehab. Services To Young Adults with Emotional Disturbances
Interest Area: Transition Strand
Kate Donegan, Harry Carson

He Ain't Heavy.....He's My Brother
Interest Area: Family Strand
Amanda Segroves, Anita Marguerite, Cheryl Crosby, Dan Carter, Sylvan Segroves, Wendy Atherton

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Facilitating Community Membership
Interest Area: Advocacy
Paul Selby, Wendy Welsch

Culturally Competent Family Supports in Western Massachusetts: Work in Progress
Interest Area: Multicultural Strand Douglas McCallum, Barbara Morrell, Christine Lynch, Dana Dansereau, Josefina Castillo, Michael Romanovitch, Pat Ononibaku , Raquel Rodriguez

Social Justice Teaching in Inclusive Classrooms
Interest Area: Inclusive Education
Mara Sapon-Shevin

The Textbook Presence:Disability as Decor or Politics
Interest Area: Inclusive Education
Virginia Epps, Paula Neville

Self-Advocate Leadership
Interest area: Advocacy Strand
Cathy Ficker-Terrill, Tia Nelis

Innovative Models of Dementia Care for Older Adults with Developmental Disabilities
Interest Area: Aging Strand
Lauren Bertagna, Marcy Nelson, Matt Janicki

Empowered Families Vitalize Change to Missouri's System
Interest Area: Family
Suzanne Woolever, Deana O'Brien

Crackerbarrel on Implementation Issues in Support Employment and Transition
Interest Area: Employment Strand
Mike Callahan

Thursday, December 9, 1999 11:30 AM - 12:30 PM

Characteristics of an Inclusive Pre-service Program to Prepare Teachers
Interest Area: Personnel Preparation
John Filler, Jeffery Gelfer, Peggy Perkins

Maintaining the Focus on Learning: Effective School & Classroom Management of Disruptive Behaviors
Interest Area: Students Who Severely Challenge Schools
Daniel DeMarle

Reforming Initial and Ongoing Professional Development
Interest Area: Personnel Preparation Strand
Dianne Ferguson, Elizabeth Kozleski

Advisor Roles, Responsibilities and Issues in the Self-Advocacy Movement
Interest Area: Self-Determination Strand
Mary Hayden, Debbie Prockner, Jean Bowen, Leighann Reusche

People Who Need People: The Direct Service Workforce
Interest Area: Management Issues
Nicole Janer, Christine Chang, Michelle Stone, Prudence York

Philadelphia Inclusion Network - Welcoming All Children
Interest Area: Early Childhood Strand
Lillian McCuen, Philippa Campbell, Suzanne Milbourne

I'm Somebody: Personal Safety Skills for Children with Disabilities
Interest Area: Sexuality Strand
Pnina Tobin

Technology, Web Based Instruction, Staff Development and Postitive Behavior Support
Interest Area: Personnel Preparation
Wayne Sailor, Amy McCart, Jody Britten, Rachel Freeman

Beyond Normalization
Interest Area: Positive Approaches
Masoud Moazami

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Are you facing the daunting prospects of going through a due process hearing to get a good program for your child? Have you been asked by a parent to be an expert witness and you have no idea what that might involve? Do you want to hear from others who have been through this experience and find out strategies that worked for them? Gail McGregor and Judy Gran have organized this strand to include sessions that will address these issues and more. As an added support to families, a number of attorneys will be available in "consultation rooms" throughout the day of strand so that families can sign up for a time to meet with an attorney to receive legal advice about issues of concerns regarding their child's school program.

With the support and coordination of Judith Gran from the Public Interest Law Center of Philadelphia, a number of lawyers with expertise in inclusive schooling practices will be available to provide individual consultation to families attending the conference. This free service is being offered in conjunction with the Due Process Strand. Sign up for this great opportunity to get some advice and information about people in your community that can support your efforts to obtain an inclusive educational program for your child.

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Thursday, December 09, 1999 11:30 AM - 12:30 PM

Are Empirical Research and Science Still Important in TASH?
Interest Area: Research
Robert O'Neill

How to Implement Natural Support Strategies in Employment Settings
Interest Area: Employment Strand
Keith Storey, Denise Mautz, Nicholas J. Certo, Shelly McHugh

Students Who Severely Challenge Schools: Supporting General Education Staff
Interest Area: Students Who Severely Challenge Schools
Pamela Holmdal, Joan Pabisz-Ruberton

Community-Based Literacy Program Design for Adults w/ Mental Retardation
Interest Area: Community Living
Robin Reale

First Steps in Making High Schools More Inclusive
Interest Area: High School Inclusive Education
Alan Ripp, Karen Zimbrich

Partnership Toward Jobs
Interest Area: Transition Strand
Helene-Marie Collins, Sharon Bargiel

Four Stories of Inclusion: The Impact of Individualized Technical Assistance
Interest Area: Inclusive Education
Donna Gilles

Preparing School Professionals to Supervise Paraeducators
Interest Area: Paraeducator Strand
Nancy French

The Difference Between "In" and "With"
Interest Area: Inclusive Education Strand
Carol Tashie

Creative Marketing to Welcome Everyone! What Images and Words Send Messages of Inclusion
Interest Area: Leisure and Recreation Strand
Cindy Burkhour

The Role of Spirituality in Leaders for Justice and Equity
Interest Area: Spirituality Strand
Maureen Keyes

Thursday, December 9, 1999 11:30 AM - 1:45 PM

Conducting Functional Behavioral Assessments & Designing ISP's for Students at School
Interest Area: Positive Approaches Strand
Tim Knoster

Thursday, December 9, 1999 12:45 PM - 1:45 PM

Agency Conversion from Group Homes to Individualized Alternatives
Interest Area: Community Living Strand
Pam Walker, Jeffrey L. Strully, Patricia Fratangelo

Victims: No Longer Alone
Interest Area: Criminal Justice Strand
Leigh Ann Davis, Cheryl Guidry-Tyiska

CARF Accreditation Update
Interest Area: Management
Dale Dutton

General Education Access: A State Department of Education's Perspective
Interest Area: Alternate Assessment
Nanette Olivier, Gayle Melville, Margaret Lang

The Actions of Including ALL Students
Interest Area: Inclusive Education
Christine Salisbury, Kathy Chapman

Teaching Positive Behavior Support: How to Help Schools Implement IDEA 1997
Interest Area: Personnel Preparation Strand
Ethan Long, Don Kincaid, Scott Spaulding

Family-focused Strategies for Surfing the Internet's Disability Resources
Interest Area: Family Strand
Emily Watts

I Feel More Like an Assistant than a Teacher: Maximum Participation or all Teachers
Interest Area: Inclusive Education
Linda Davern

The Role of Paraeducators in Inclusive Classrooms: Their Own Perspective
Interest Area: Paraeducator Strand
June Downing, Denise Clark, Diane Ryndak

Teacher Preparation: Inclusion of Service-Learning Projects Involving Persons w/Disabilities
Interest Area: Higher Education
Jean Hauser

Inclusive Education Practices for Supporting Students Who Use Augmentative Communications
Interest Area: Inclusive Education Strand
Rae Sonnenmeier, Michael McSheehan

Increasing Interaction at a Distance: Benefits Derived from Broadcast Journalism
Interest Area: Distance Education Strand
Fred Spooner

A Survey for Inclusion of Latino Parents in School Programs
Interest Area: Multicultural Strand
Ming-Gon John Lian, Sandra Fontanez-Phelan

Parents' Perspectives on Important Practices in Communication for Children Who are Deaf-Blind
Interest Area: Family Strand
Kathleen McNulty, Blanche Stetler, Jerry G. Petroff

Continued on page 16

Continued from page 15

Disabilities and the Internet
Interest Area: Advocacy Strand
Jacky Comforty, Lisa Comforty

Evaluating the Processes and Outcomes of an Inclusive School Program
Interest Area: Research
Stacy Dymond, John Kregel, Martha Nigrelli

From Institutions to Inclusion - A Roadmap for Success
Interest Area: Management
Patty Veselsky, Marti n Romero-Mitchell, Max Chmura

Florida Network on Deaf-Blindness: Implementing Successful Transition
Interest Area: Transition Strand
Lauri Triulzi, Donna Gilles, Melinda Morrison

We're All People First
Interest Area: Ethics/Rights
Ann Marie Campbell

Thursday, December 9, 1999 12:45 PM - 1:45 PM

The Vermont Self-Determination Project
Interest Area: Self-Determination
Karen Topper, Dawn Arsonault, Kim Daniels, Maggie Daniels, Sue Ainroth

The Alternative Assessment Requirement: Opportunity to Bring About Meaningful Curriculum Change
Interest Area: Urban Strand
Alison Ford

Inclusive Early Childhood Programs — Rewards and Roadblocks
Interest Area: Early Childhood Strand
Roger Bailey

Assessment as a Way of Seeing and Being
Interest Area: Inclusive Education
Terri Jo Smith

Self-Determination Curriculum Sampler
Interest Area: Self-Determination Strand
Diane Browder, Bob Algozzine, David Test, Meagan Karvonen, Wendy Wood

Body and Soul: Sexuality in Context
Interest Area: Sexuality Strand
David Hingsburger

Perceptions of Health & Aging by Women with Intellectual Disabilities
Interest Area: Aging Strand
Allison Brown, Carol Gill

Recreation and Sports "Just Do It": Signing up: What to do, say, ask for, share, etc.
Interest Area: Leisure & Recreation Strand
Cindy Burkhour

The Role of Spirituality in One's Life: Coursework in Higher Ed. to Prepare Leaders for Justice
Interest Area: Spirituality Strand
Colleen Capper

Thursday, December 9, 1999 12:45 PM - 3:00 PM

What Hollywood Tells Us About Education Today
Interest Area: Inclusive Education
Sharon Freagon, Ann Kremer, Bill Peters, Theresa Montalbano

Acting Locally for Systems & Organizational Change in Employment Services
Interest Area: Employment Strand
John Butterworth, Sheila Fesko

Continued on page 17

Join Anne Smith and Zuhy Saheed for the International Inclusive Education strand as they explore dimensions of inclusion/exclusion around the world. It will be structured for interactive discussion. Following brief panel presentations, both presenters and participants will respond to focused discussion questions to identify emerging themes around the global inclusive movements as well as to highlight activities in various nations and regions across several continents. The day will end with some strategic networking and discussion about how TASH members can become more actively involved in international inclusive education efforts.

This strand features a panel of dynamic speakers including: Carol Berrigan, Dora Bjarnason, Mary Ann Curulla, Shalini Dave, Rosario Diaz-Greenberg, Sue Hamre-Nietupski, Kenn Jupp, Levan Lim, Mary McNeil, Rhonda Neuhaus, Kala Parasuram Shrikanth, Florence Seah, Susan Sygall, Jacqueline Thousand, Rich Villa, June Yen Siew Sim.

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Herb Lovett Symposium: "Knowledge vs. Wisdom: What do we know and what do we think we know?"
Interest Area: Ethics/Rights
Anne Donnellan, Sally Young

An Interactive Process for Assessing Nonsymbolic Communication: Pilot Findings
Interest Area: Communication
Martha Snell, Filip Loncke

Focusing on the point of Transition
Interest Area: Transition Strand
Nicholas Certo, Caren Sax Denise Mautz, Holly Wade, Ian Pumpian, Kimberley Smalley

Implementing Employment Services for People With Disabilities through a One Step Career Center
Interest Area: Employment Strand
Mike Callahan

Thursday, December 9, 1999 2:00 PM - 3:00 PM

To Be or Not to Be Instructive in Inclusive Settings
Interest Area: Paraeducator Strand
Mary Lasater

Preliminary Findings from the Self-Determination Synthesis Project
Interest Area: Self-Determination Strand
Diane Browder, Bob Algozzine, David Test, Meagan Karvonen, Wendy Wood

Important Characteristics of Inclusive Community Preschool & Daycare Programs
Interest Area: Early Childhood Strand
John Filler, Barbara Purvis, Catherine Lyons, Cynthia Lau, Jeffrey Geller

Including ALL Students in the Regular Classroom: Strategies & Techniques
Interest Area: Inclusive Education
Daniel DeMarle

You've Got to Have Friends: Mothers' Work and Disability
Interest Area: Research
Perri Harris

Shifting the Balance: Steps and Strategies to Increase Community Support
Interest area: Community Living Strand
Susannah Joyce

Continued on page 18

PRESIDENTIAL TASK FORCE ON EMPLOYMENT OF ADULTS WITH DISABILITIES

TO HOLD TOWN HALL MEETING AT TASH CONFERENCE: DECEMBER 8, 1999 2:30 - 7:30 PM

The Presidential Task Force on Employment of Adults with Disabilities is holding a series of Town Hall Meetings across the nation to give key stakeholders the opportunity to provide direct input to Task Force Members. The Task Force will hold its third Town Hall Meeting on December 8, 1999, in concert with the TASH conference.

The Presidential Task Force is charged with creating a "coordinated and aggressive national policy to bring adults with disabilities into gainful employment at a rate that is as close as possible to that of the general adult population." The purpose of this Town Hall Meeting is to invite you to address the alarming unemployment rate among Americans with disabilities. Particular focus is requested at this meeting on **expanding employment opportunities for people with the most significant disabilities, including strategies for increasing choice and community based employment, use of technology, and business/entrepreneurial development.** TASH members are encouraged to participate in this unique opportunity. Additional information will be provided in a subsequent mailing. For questions, please contact Denise Marshall at (410) 828-8274, ext.103.

Additional information about the Task Force is available at www.dol.gov

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Training School Psychologists to Facilitate Inclusion of Students with Disabilities
Interest Area: Personnel Preparation Strand
Christine Cole, Lori McCann, Tara Skibitsky

Reviewing Sex Education Curricula for Persons with Disabilities: Savvy Consumerism 101
Interest Area: Sexuality Strand
Pamela Wolfe, Wanda Blanchett

Building Foundations: Attaining Alertness/Attention in Children with Severe Disabilities
Interest Area: Students Who Severely Challenge Schools
Robin Greenfield, Gail Brown

Safe City Settings: Congregate Living - Non-intrusive Supports Providing for Safe Community Living
Interest Area: Community Living
Debra Haines, Margaret Griffin

Family Support in Washington State: The Family Support Opportunity Program
Interest Area: Family
Lyle Romer, Beth Aigbe

Blowing in the Wind: Developing a Culturally Competent Conference for Native Americans
Interest Area: Multicultural Strand
Lynda Baumgardner

Issues in Alternative Medicine (Healing Modalities)
Interest Area: Spirituality Strand
Alan Berger

Access to Academics: The "Second Generation" of Inclusion
Interest Area: Inclusive Education
Doug Biklen, Diana Straut, Paula Kluth

Videoconferencing Technology: Setting Future Directions in Personnel Preparation
Interest Area: Distance Education Strand
Martin Agran, Richard Kiefer-O'Donnel

I Don't Have to Hurt Myself: Functional Communication Training
Interest Area: Communication
Cheryl Mercal

Developing Advocacy Networks for a Stronger Voice
Interest Area: Advocacy Strand
Vendella Collins, Claudia Wise, Donald Trout

Teaching Word Problem-Solving in Inclusive Settings: A Schema Based Approach
Interest Area: Inclusive Education
Caroline DiPipi, Edward Grasso

Weaving Tapestries of Inclusion: Seven Threads to Strengthen Membership
Interest Area: Inclusive Education
Terri Vandercook

Breaking Down the Barriers: Preparing Teachers to Teach All Students
Interest Area: Personnel Preparation
Liz Keefe, Julia Sherba de Kaia Tollefson, Leslie M. Lederer, Loretta Salas, Pam Rossi

Practical Approaches to Supporting Older Families in Making Future Plans for their Relatives
Interest Area: Aging Strand
Alan Factor

Achievement of High Standards via the General Education Curriculum
Interest Area: Inclusive Education Strand
Cheryl Jorgensen, Douglas Fisher

Sports & Recreation Inclusion Supports: What are they and how do you get them?
Interest Area: Leisure and Recreation Strand
Tracey Crawford

Victims with Disabilities
Interest Area: Criminal Justice Strand
Audrey Badger, D.J. Stemmler

Thursday, December 9, 1999 2:00 PM - 4:15 PM

Building Inclusive Education in a Los Angeles School District
Interest Area: Urban Strand
Mary Falvey, Nancy Franklin, Ricki Light, Whitcomb Haslip

Crisis, What Crisis? Supporting Persons with Challenging Behaviors in the Community
Interest Area: Positive Approaches Strand
Axel Junker, Behg Garrey, Dan Rossiter

A Transformation of Services for Students 18-21 Years Old
Interest Area: Transition Strand
Robin Wood

A TASH Family Genealogy
Interest Area: Family Strand
Lynda Atherton, Adelaide Comegys, Bud Frederick, Jeffrey L. Strully, Thomas Powell

Thursday, December 9, 1999 3:15 PM - 4:15 PM

The Self-Determination Scale
Interest Area: Self-Determination Strand
Daniel Baker, Gary Sappington, Rhonda Kelsch, Rob Horner, William Ard

Support for Harmful Actions
Interest Area: Positive Approaches
Doug Gragson, DeAnna White

Academic Engagement in High School: Creating Opportunity for All Students
Interest Area: High School Inclusive Education
Robin Smith

Our Turn Now: Including All Children in Child Care
Interest Area: Early Childhood Strand
Marilyn Dunning, Karen Martin

Instructional Personnel Perspectives on Effective Inservice Practices
Interest Area: Personnel Preparation Strand
William Sharpton, Cathie Koss, deVergne Goodall, Linda Flynn, Margaret Lang, Nanette Olivier

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Songs of Liberation and Community
Friday, 8:00 – 10:00 PM

With Mara Sapon-Shevin and Mayer Shevin and folk singers from the Chicago area

Songs will include (among others) "We Shall Not Be Moved," "Ain't Gonna Study War No More," "De Colores," and "We Shall Overcome"

People struggling for their rights have always used music and singing to stay connected and share their stories with others. Music is the model of an inclusive activity in which everyone can participate and through which we learn the joy and power of many voices together.

The civil rights movement, the women's movement, the movement for gay liberation and the disability movement have all produced wonderful songs that inspire, educate, and lift our spirits.

Local Chicago folk singer will be joining with a number of TASH Members to lead an evening of song, celebration, and musical fun.

Come to sing, listen, clap, and meet old and new friends, all are welcome... you don't have to be a "singer" to come and enjoy yourself.

If you have songs you would like to share at this gathering please call us at 315-425-0251, leave a note at the TASH Information Table at the Conference or let us know at the beginning of the gathering.

Herb Lovett SYMPOSIUM

"Knowledge versus Wisdom: What do we know and what do we think we know?"
December 9th, 12:45 - 3:00 p.m.

Before his untimely death in 1998, Herb Lovett had been developing a major work around mythology in the fields of special education, rehabilitation, service and care. He proposed a series of questions to challenge himself and us all regarding our stories about what we know and think we know on topics such as mental retardation, changing behavior, autism, intelligence, support, stigma and so forth. This symposium, the first in what we hope will be an annual event, will feature a number of TASH members addressing these topics. The format will be open conversation, which we hope will encourage an ongoing dialogue and self-reflection during the TASH conference and beyond.

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Putting the "IN" into Inclusion
Interest Area: High School Inclusive Education
Julie Schackmann, Nancy Spejcher, Pandora Taylor, Vicki Niswander

AAC in Guatemala
Interest Area: Multicultural Strand
Janet Duncan

Preparing Secondary Educators for Inclusive Education: Crossing the Lines
Interest Area: Higher Education
Alice Udvari-Solner, B. Bradford Brown

Web-based Inservice Instruction for Practicing Teachers in Severe Disabilities
Interest Area: Distance Education Strand
Barbara Ludlow, John Foshay, Michael Duff, Sara Brannan

Shifting the Special Education Paradigm to Realize Inclusive Schooling
Interest Area: Inclusive Education Strand
Beth Schaffner, Barbara McKenzie

Self-Employment
Interest Area: Community Living Strand
Michelle Flynn, Joe Wykowski

Everybody Belongs: Educational Supports and Advocacy Strategies for Inclusion
Interest Area: Inclusive Education
Nila Benito, Georgia Pappas

Crackerbarrel on Paraprofessional Issues
Interest Area: Paraeducator Strand
Pat Mueller, Anna Lou Pickett, Michael Giangreco, Patricia Mueller, Patrick Schwarz

Promoting Choices & Options in the Community that Support Later Life Transition
Interest Area: Aging Strand
Elizabeth DeBrine, Tia Nelis

Financing Inclusion Supports in Recreation and Sports: How do they do it?
Interest Area: Leisure and Recreation Strand
John McGovern

Thursday, December 9, 1999 3:15 PM - 5:30 PM

Disability and Social Change: An Exercise in Perspective
Interest Area: Advocacy Strand
Genevieve Ameling

Breaking the Barriers: Enhancing Individual Choice and Opportunities
Interest Area: Research
Mary McCarthy, Laura Stough, Nicole Caldwell

A 12-Step Program for Recovering Modernists
Interest Area: Transition Strand
Laura Owens-Johnson, Diane Ormsby

Leadership for Inclusive & Continuous School Improvement
Interest Area: Inclusive Education
Elizabeth Kozleski, Dianne Ferguson

Successful Job Development Using Employer-Tested Employment Practices
Interest Area: Employment Strand
Melinda Mast, Joan Sweeney

Be What You're Looking For: Family Support by Families
Interest Area: Family
Terri Devine, Chuck Rinchiuso, John Fogarty, Kim Orlando, Linda Rinchiuso, Lisa Reninger, Melinda Zambito, Mike Grunewald, Mike Reninger, Pat Fogarty, Patti Rizzetto, Peggy Grunewald, Sandy Pazerunas

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Spitituality and Teaching: One Teacher's Perspective
Interest area: Spirituality Strand
Madeline Hafner

From Hawaii to Maryland - A Compilation of Qualitative Case Studies in Self Determination
Interest Area: Self-Determination
Anita Yaskauskas, Ellen Fisher, Joan Bernotsky, Susan O'Connor

Person Centered Approaches - Much More than Planning
Interest Area: Management
Rick Tutt

An Ethnographic Perspective on Consultation for Inclusion
Interest Area: Inclusive Education
Michael McSheehan, Rae Sonnenmeier

Unlocking Maryland's Waiting List
Interest Area: Self-Determination
Kathy Perkins, Diane Coughlin

Alex's Gift: Belonging From First Grade to Graduation and Beyond
Interest Area: Inclusive Education
Cheryl Fisher, Alex Nickels, Achel Nickels, Tara Todhunter

Alternative Assessment Research Studies
Interest Area: Alternate Assessment
Harold Kleinert, Jacqueline Kearns, Karen Nowak, Matt Turner, Michelle Slone

IDEA Mediation: Parents and Service Providers Working Together
Interest Area: Family
Greg Abell

Growing Jobs: The Rural Route to Creative Employment
Interest Area: Employment Strand
Cary Griffin

Sexuality and Sexual Expression: Open Forum
Interest Area: Sexuality Strand
Ann Heler, Bonnie Shoultz, Wanda Blanchett

Ending the Silence: Vocabulary and Strategies for Enhancing Communications
Interest Area: Criminal Justice Strand
Diane Nelson Bryen, Beverly Frantz

Thursday, December 9, 1999 4:30 PM - 5:30 PM

Desperate Respite
Interest Area: Family Strand
Nancy Olson

Unsolved Mysteries.....Solved!
Interest Area: Independent Living
Nancy Moore, Julie Guitard, Margaret Cantey

Hey, What About the Physical Education Teacher's Involvement in Transition
Interest Area: Transition Strand
Joanne Suomi

All Children Together: Creating Inclusive Child Care Option
Interest Area: Early Childhood Strand
Peggy Florio, Pamela Miller

Achieving Inclusion through the IEP Advocacy Process
Interest Area: Inclusive Education
Selene Almazan, Patricia Cox

Behavioral Technology in Support of Values
Interest Area: Positive Approaches Strand
Gary LaVigna

Supporting Meaningful Classroom Participation for Students using a Communication Device
Interest Area: Communication
Pam Harris, Pamela J. Harris, Stephanie Williams

Teaching Students to Support Themselves in General Education
Interest Area: Inclusive Education
Martin Agran, Carolyn Hughes, Michael Wehmeyer

Making Recreation a Reality: Who can do What to Get it Going in Your Community?
Interest area: Leisure and Recreation Strand
Cindy Burkhour

International Human Rights Advocacy for People with Mental Disabilities
Interest Area: Multicultural Strand
Eric Rosenthal, James W. Conroy, Mary F. Hayden

Practicing What We Preach: Restructuring Higher Education Teacher Preparation Programs
Interest Area: Inclusive Education
Barbara Ayres, Bobbi Schnorr

Ten Years of Distance Learning: Impact on Severe Disabilities in Kentucky
Interest Area: Distance Education Strand
Belva Collins, Ann Griffen, Jennifer, John W. Schuster, Meada Hall

Bill's Supported Living Arrangement
Interest Area: Community Living Strand
Bill Coffelt

Before You Write Another Behavior Plan - Stop!
Interest Area: Positive Approaches
Larry Douglass

So We're Out There Now, But What Are We Doing? Blending Community Based Instruction & Career Planning
Interest Area: Personnel Preparation Strand
Beth McKeown, Julie Marcial, Mary Barnes, Patricia Ann

Person-Centered Planning and Self-Determination
Interest Area: Self-Determination Strand
Marijo McBride, Brian Abery

The Health and Well Being of Adults with Down Syndrome
Interest Area: Aging Strand
Dennis McGuire

Crackerbarrel on Urban Issues
Interest Area: Urban Strand
Lou Brown, Alison Ford, Anne C. Smith, Mark Doyle

— Thursday Poster Sessions —

Thursday Poster Sessions I 11:30 AM - 1:45 PM

Implementing Inclusive Education in an Urban Setting
Interest Area: Urban Issues
Joy Rogers, Mary Lynn Cavey

The Team Approach in an Integrated Kindergarten Class: Teacher Collaboration
Interest Area: Early Childhood
Lori Gackenheimer

Representation of Disability in Counselor Education Textbooks
Interest Area: Higher Education
Nancy Rosenau

Successful Collaboration: Mid South ACT & the RISE Project
Interest Area: Inclusive Education
Paul Ayers, Karen Anderson, Tom Buggey

Wise People Travel to Discover.....Themselves!
Interest Area: Independent Living
Margaret Cantey

The Best of Both Worlds...Including a Seventh Grader with Autism
Interest Area: Inclusive Education
Patricia K. McDaid

Inclusion Project: Parent Mentors
Interest Area: Inclusive Education
Mary Ann Mieczkowski, Kim Trescott, Vicki Spence

Kidspaces: Home to Support Self-Determination for Children with Disabilities
Interest Area: Self-Determination
Mary Jane Brotherson, Christine Cook

Family Resourc Project: Empowerment of Parents of Children with Disabilities
Interest Area: Family
Alan Reiman, Kathy Fitzgerald, Karen Ward

Supportive Classrooms and the Quality of Inclusion: A Research Study
Interest Area: Research
Ann Dillenbeck, Wayne Fox

Providing Services for Families of Children w/ Autism Living in Geographically Distant Areas
Interest Area: Family Autism
Jennifer Symon, Robert Koegel, Lynn Koegel

Thursday, Poster Session II 3:15 PM - 5:30 PM

Same Window, New View: Print Media and Persons with Disabilities
Interest Area: Advocacy
Sylvia Martin, Susan Catlett

Perceptions of Challenging Behaviors of Learners with Dual Sensory Impairments
Interest Area: Students Who Severely Challenge Schools
MaryAnn Demchak

Parents Ponder Inclusion
Interest Area: Family
Deanna Horstmeier,

Stepping Up to the Plate
Interest Area: Self-Determination
Nancy Myers

Positive Peer Pressure: Using Peers to Assist Students with Special Needs
Interest Area: Inclusive Education
Carolyn Auld

Leadership Today Society of Alberta: Partners in Effective Decision Making
Interest Area: Self-Determination
Sandra Mak

The Use of Visual Clues in the Classroom
Interest Area: Inclusive Education
Samantha Bortz

Adaptation and Modification Project
Interest Area: Positive Approaches
Donald La Fave

Moving Out to Move Forward: How We Do C.B.I.
Interest Area: Community Living
Chuck Nachtrab

From Concept to Reality - Community Options Conversion Project
Interest Area: Employment and Careers
Diane D'Orazio, Kerry Brennan, Dave Vasa, Andy Phillips

Long Term Impacts & Processes of PBS
Interest Area: Research
Marilyn Lauer, Lynn Koegel, Erin McNerney, Josh Harrower, Robert Koegel

Believe in Yourself: The Road to Becoming a Self-Advocate
Interest Area: Advocacy
Sheri Glasser, Margaret Stout

Friday, December 10, 1999 8:00 AM - 9:00 AM

Has Special Education Lost Its Moral Bearings?
Interest Area: Personnel Preparation
Carl Lashley

Present Away! Developing Presentation & Facilitation Skills
Interest Area: Management
Mary Fitzgerald

Preparation of Teachers to Meet Needs of Students w/Severe Disabilities
Interest Area: Personnel Preparation
Denise Clark, Christy Lee Holthaus, Diane Ryndak

Research Based ADA Technical Assistance Maximizing Effective Implementation of Employment Provisions
Interest Area: Research
Susanne Bruyere, Robin Jones

The Spirituality of Friendship
Interest Area: Spirituality Strand
Sue Henshaw

Comprehensive Positive Behavior Supports Incorporating Biobehavior
Interest Area: Positive Approaches Strand
Craig Kennedy, Kristine Jolivette, Terry Long, Travis Thompson

Replacing Prelinguistic Behaviors with Functional Communication
Interest Area: Research
Deborah Keen

A Day in the Life
Interest Area: Inclusive Education
Lawrence Lieberman

Examining Communicative Repairs in Young Children Who Lack Language
Interest Area: Communication
Jim Halle, Barbara Phillips, James Halle, Yvonne Carey

A Seven-Year Partnership: A Support Circle Tells Their Story
Interest Area: Transition Strand
Emily Ellis, Carole Gothelf, Eric Doughty, Geri Smith, Mary Kay Brown, Patrick Russell, Sheila Kresch

Ohio's Self-Determination Project: How Four Local Pilots Soared
Interest Area: Self-Determination Strand
Hap Hinkle, Dana Charlton, S. Hap Hinkle

If It's Day 6 It Must be Middle School: Creating an Inclusive Middle School Environment
Interest Area: Inclusive Education
Patricia McDaid, Paula Nargi

Developing Creative Thinking Skills in Preservice Teachers
Interest Area: Personnel Preparation
Pamela Gent

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Thank You! to the following Official Sponsors for their support of the 1999 TASH Annual Conference!

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www.ci.chi.il.us/Disabilities/

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Project RSVP: Expanding Opportunities for Vocational Rehabilitation
Interest Area: Employment Strand
Jane Roth, Lisa Jarrett

Let Us Tell You How: Spreading the Americorps Message of Self-Advocacy and Self Determination
Interest Area: Advocacy Strand
Laurie James, Bridget O'Donnell, Lisa Obrist, Lori Kelso, Scott Wing

The Making of an Inclusive Teacher
Interest Area: Professional Development Strand
Kelly Aramaki, Anna Whitesel, Ellen Rice, Jane Hill, Sue Thomas

Navigating the Medical Mine Field
Interest Area: Advocacy Strand
Deana O'Brien

Systems Change: Staying Afloat in Changing Waters
Interest Area: Inclusive Education
Gail McGregor, Christine Salisbury, William Sharpton

Religion/Faith Crackerbarrel
Interest Area: Religion/Faith Strand
Kim Farrington

Supporting Children with Autism Spectrum Disorders in Typical Classroom Settings
Interest Area: Autism Strand
Cathy Apfel, Rae Sonnenmeier

Supporting Healthy Sexuality in Adults with Developmental Disabilities
Interest Area: Criminal Justice Strand
Terri Pease

Four Year Evaluation of Louisiana Home of My Own Project
Interest Area: Community Living Strand
Phil Wilson, Jane M. Everson, Kirk Anderson, Michael Rando, Nancy Robertson

Friday, December 10, 1999 8:00 AM - 10:15 AM

Future & Special Needs Planning
Interest Area: Family
Barton Stevens

Subtleties of Person-Centered Transition Planning: Mastery through Process & Accomplishment
Interest Area: Transition Strand
Denise Ferrara, Craig Michaels

Teaching and Learning in Multilevel Classrooms
Interest Area: Inclusive Education
Catherine Bove, Connie Miller, Dave Rice, Lori Eshilian

Individual Supported Employment in King County: An In-Depth Anaylsis
Interest Area: Employment Strand
Lyle Romer, Beth Aigbe, Ray Jensen

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Emma Rose Scholarship

Funds Available for Families to Attend the TASH Conference

Through the generosity of the Jacobs Family, TASH is pleased to announce the creation of the Emma Rose Scholarship Fund. The purpose of the scholarship fund is to foster the growth of parent advocacy and activism by honoring two parents each year who have made a difference in the lives of people with disabilities.

We are accepting nominations (self-nominations are encouraged!) for this year's scholarship. Scholarship recipients will have their conference registration fee waived and their travel and hotel expenses will be covered. Scholarship recipients will be invited to present at the TASH conference. Recipients are asked to commit to raising $200 annually for the next two years toward the continuation of the scholarship fund. This year's scholarship recipients should be willing to participate in selecting next year's recipients.

To apply, send a letter describing why you or the person you are nominating should be selected for this honor. Letters should be received by October 15th. Send to: Nancy Weiss, TASH, 29 W Susquehanna Avenue, Suite 210, Baltimore, MD 21204. Letters also can be sent by e-mail (nweiss@tash.org) or fax: 410-828-6706. For questions, call Nancy at 410-828-8274, ext. 101

Donations for the Emma Rose Scholarship are being accepted and can be made to TASH at the address above.

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FREE! Disability Resource Catalog

VIDEOS • SOFTWARE • CD-ROMS

NEW 1999 Catalog *lists over 100 resources for staff development and skills training for people with disabilities. Includes award winning videos, software, books and board games on employment, inclusion, transition, advocacy, disability awareness, sex ed., friendmaking, and more.*

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WWW. PDASSOC.COM

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Self-Determination for Infants, Toddlers, & their Families
Interest Area: Family Strand
Mitch Kremer

How Big is Your Circle?
Interest Area: Creative and Performing Arts
Jeff Moyer

Never Take Physio-Therapy from a Therapist on a Diet!
Interest Area: Ethics/Rights
Norman Kunc, Emma Van der Klift

Moving to Inclusive Services in Chicago Schools
Interest Area: Urban Strand
Ruth Henning, Sharon Freagon, Sue Gamm, Yvonne Williams

For All Abilities
Interest Area: Leisure and Recreation
Cindy Moyes, Nicki Compton

Doing Inclusion: When a Child has Severe Health Care Needs
Interest Area: Special Health Care Needs Strand
Cynthia Levine, Arlene Lockenwitz, Caitlyn Foley, Cindy Balboni, Jim Kane, Joan Quinn, Joe Dupelle, Rhonda Majkowski

Autism, Personhood and Self: One Woman's Story
Interest Area: Ethics/Rights
Sally Young, Carolyn Nuyens, Sandra Radisch

Awakening the Sleeping Giant in the New Millenium: People with Disabilities. Their Voting Rights, Political Voice, and Electorial Opportunities
Interest area: Governmental Affairs
Lawrence Gorski

Friday,
December 10, 1999
9:15 AM - 10:15 AM

Infusing Self Determination into Personnel Preparation
Interest Area: Self-determination Strand
Thomas Holub, Courtney Moffatt, Ellen Browning

A Model for Deciding Whether a Student Needs Paraeducator Support
Interest Area: Paraprofessional
Michael Giangreco

Adapting the Curriculum in the Inclusive Setting Using Assistive Technology
Interest Area: Assistive Technology
Randi Agetstein, Rick Metheny, Sheree Witt, Terri Crawford

A Continuum of Natural Support Strategies Involving
Interest Area: Employment Strand
Janis Chadsey, Debra Shelden

Assessment and Intervention for Sleep Disorders
Interest Area: Positive Approaches Strand
Robert Horner, Craig Kennedy, Mark Harvey, V. Mark Durand

The Power of Teaching
Interest Area: Professional Development Strand
Freddie Vaughns

Preservice and Inservice Education in Urban Settings
Interest Area: Personnel Preparation
Mary Falvey, Jennifer J. Coots, Marquita Greynot-Sheyer

Related Services in Inclusive Schools: Exploring a Primary Therapist Model
Interest Area: Related Services
Beverly Rainforth

Demanding Our Place at the Table: Learning to Make a Difference
Interest Area: Advocacy Strand
Laurie Kimball, Victoria Wood

1999 Announcing the TASH Conference Yearbook

▼▼▼

1999 will be the inauguration the TASH Yearbook. The Yearbook will be a compendium of selected articles describing many of the conference presentations. A yearbook differs from conference proceedings in that a yearbook is a selection of articles on sessions that will be of most interest to TASH members and others, rather than a compilation of articles on all sessions presented.

The material will be in a form that integrates and summarizes the information presented in each session approved for inclusion. It may be a written manuscript, photo(s), a poem, a description of a personal experience, a combination, or any other format that lends itself to publication. The goal is to compile a book that includes a range of materials that are reflective of the full range of topics of interest to the TASH audience.

Session chairpersons are invited to submit written material for the Yearbook. The article is due to the TASH Central office by Monday, January 17th (however, we recommend you submit it prior to the conference if possible). Submitted articles must not have been published previously in this form and should reference previous publication of any of the information. All articles will be sent to at least three reviewers. Final decisions about inclusion in the Yearbook will be made by co-editors Douglas Fisher, Craig Kennedy, and Barbara Buswell. Decisions will be based on the ratings of reviewers.

The Yearbook will be available for pre-sale at a reduced rate of $25.00 in conjunction with conference registration. Individuals attending the 1999 conference can indicate on their conference registration form an interest to order one or more copies of the Yearbook. Payment will be made along with payment for conference registration. Individuals who do not attend the conference can order the Yearbook for $35.00.

If you have any questions about a submission to the 1999 TASH Yearbook, please contact Doug Fisher at 619-594-2507 or dfisher@mail.sdsu.edu

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Keeping the Spirit: Processes for Motivation & Renewal
Interest Area: Spirituality Strand
Carole Gothelf, Cindy Ruetsch, Jerry G. Petroff

Building Linkages between Assessment and Instruction
Interest Area: Inclusive Education
Jan Writer

Use of Person Centered Planning for Transition Planning: A Research Study
Interest Area: Transition Strand
Brigid Flannery, Rob Horner

Applying the Technology: Overcoming Challenges to Meaningful & Effective Inclusion
Interest Area: Inclusive Education
Chris Oliva, Donna Lehr, Edna Barenbaum

The Great Lessons of the 20th Century
Interest Area: Management
Peggy Gould

Safety and Your Rights
Interest Area: Advocacy Strand
Cha Pope, Cherie Tessier, Dale Colin, Diana Robishaw, Michael Raymond

Enhancing Community Living of Persons with Cultural and Linguistic Diversity
Interest Area: Community Living Strand
Ming-Gon John Lian, John Donnelly, Marbella Marsh

Preparing Personnel to Offer Choice & Enhance Participation in Community
Interest Area: Personnel Preparation
Karena Cooper-Duffy

Inclusive Education: Proven Techniques for Every Classroom at All Grade Levels
Interest Area: Inclusive Education
Patti McVay, Andrea Guard, Barbara Jorgensen, Heidi Wilson, Joan Medlen

Supporting Diversity in Personnel Preparation: Inclusive Co-Instruction
Interest Area: Personnel Preparation
Debbie Gilmer, Alan Kurtz, Dennis Stubbs, Kathy Son, Lenny Berry

Early Childhood Crackerbarrel
Interest Area: Early Childhood Strand
Elizabeth Erwin, Beth Brennan

Including People with Disabilities in Faith Communities
Interest Area: Religion/Faith Strand
Kim Farrington

Modifications for Sensory Sensitivities and Movement Differences
Interest Area: Autism Strand
Cathy Apfel, Rae Sonnenmeier

Rethinking the Death Penalty for People w/Mental Retardation: A New Global Perspective
Interest Area: Criminal Justice Strand
Billy Edwards

Friday, December 10, 1999 12:15 PM - 1:15 PM

How Individuals with Autism & Other Neurological Disabilities Manage: Approaches and Strategies
Interest Area: Self-Determination
Marjorie Olney

I Should've Been in Pictures! Creating Student Portfolios
Interest Area: Inclusive Education
Mary Fitzgerald, Eve Cugini, Melissa Steed

Visually Impaired
Birth Crisis
Classroom Videos
Feeding Infants
School Safety
Tracheostomy
Down Syndrome
Inclusion in Schools
Communication
Hearing Impaired
Medications at School
Home Visiting
Parenting
Universal Precautions
Violence Prevention
Managing Behavior

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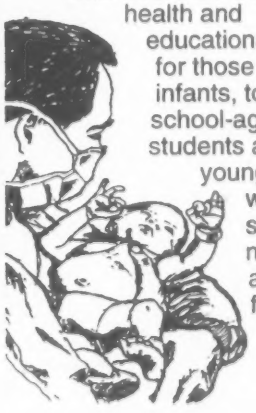
Children with special needs are our business. LMD offers the best in health and educational media for those serving infants, toddlers, school-aged students and young adults with special needs and their families.



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Inclusion and Eys? Social Skills for Students with Pervasive Developmental Disorders
Interest Area: Inclusive Education
Susan Catlett

University Partnerships to Support Collaboration, Co-Curricular Planning & Co-Teaching
Interest Area: Urban Strand
Toni Strieker, Betsy Bachman, Colleen Arnold, Constance Goodson, Ginger Joyce, Gwen Benson, Janice Monk, Kim Rostiek, Susan Jacob

Inclusion in Social/Political Activism
Interest Area: Advocacy Strand
Maria Timberlake

Alternative Treatments for Seizure Disorders
Interest Area: Special Health Care Needs Strand
Lawrence Lieberman

The Collaborative Problem Solving/Mutual Teacher Support (CPS/MTS)
Interest Area: Personnel Preparation
David Westling, Karena Cooper, Kathy Blossfield

Use of FM Assistive Listening Devices
Interest Area: Assistive Technology
Barbara Franklin

Observational Leisure Learning in Community-based Residential Settings
Interest Area: Leisure and Recreation
Maureen Wall, Stephanie Kouzoukas

Lifespan Respite: Respite Across the Ages
Interest Area: Governmental Affairs Strand
Nancy Olson

Using Cohort Groups to Improve Teacher Performance
Interest Area: Personnel Preparation
Jimmie Phillips, William Sharpton

Listening to Individuals Who Do Not Use Words to Communicate
Interest Area: Communication
Vicki Gerrits, Bonnie McLellan, Deb Buckingham, Kathy Gilman, Linda Wiger, Sarah Pitzner

Importance of Including Families in Interdisciplinary Personnel Preparation
Interest Area: Professional Development Strand
Jan Moss, Anita All

Your Visions Can Come True
Interest Area: Self-Determination Strand
Nancy Baesman, Bill Baesman

Inclusive Music Activities: Making Everyone Part of Music Making
Interest Area: Creative and Performing Arts
Mara Sapon-Shevin, Mayer Shevin

Finding Your North Star: Self-Determination & Planning Alternative Tomorrows with Hope
Interest Area: Community Living Strand
Linda Seidman, Christine Crescente, Marilyn Casey, Tina Mazurkiewicz

Parent Training & Information Centers as Collaborators in Advocacy & Empowerment
Interest Area: Family
Charlotte Des Jardins, Judith Raskin, Terri Dawson

Sister Act: Advocacy Begins in Childhood
Interest Area: Family Strand
Nancy Verderber, Katie Stollhans

Raising Our Voices: Maine's Youth Leadership Initiative
Interest Area: Transition Strand
Debbie Gilmer, Bonnie Robinson,, Elizabeth DePoy, Janet May

Surviving the Education System: A Success Story
Interest Area: Inclusive Education
Dick Hosty

The Family Network Project: Providing PBS to Families from Underserved Communities
Interest Area: Positive Approaches Strand
Bobbie Vaughn, Glen Dunlap, Lise Fox

It's My Turn in the Community
Interest Area: Early Childhood Strand
Michelle Padilla, Daneen Ruski

Expanding Inclusive Schooling: Activities and Partnerships for Systematic Change
Interest Area: Inclusive Education
Ann Halvorsen, Deborah Twett-Hall, Dona Meinders, Jacki Anderson, Linda Lee, Mary Falvey, Nancy Franklin, Pamela Hunt

Hilarity Therapy
Interest Area: Management
John Irvin

Creating Inclusive Schools in an Urban School District: A Collaborative Approach
Interest Area: Inclusive Education
Ellen Rice, Cathy Rikhye, Celia Oyler, Janice Payne, Melissa Price

Self-Advocates' Maximixing their Roles as Board Members
Interest Area: Advocacy Strand
Tia Nelis, Essie Pederson

Guardianship: Last Civil Rights Frontier
Interest Area: Guardianship Strand
Dohn Hoyle

Alternatives in Criminal Justice for People with Developmental Disabilities
Interest Area: Criminal Justice Strand
James McAfee

Using Visually Enhanced Materials to Support Communication
Interest Area: Autism Strand
Cathy Apfel, Rae Sonnenmeier

Friday, December 10, 1999
12:15 PM - 2:30 PM

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Spiritual Beliefs and Response To Disability: Inclusion into Christian Churches
Interest Area: Religion/Faith Strand
Linda Treloar

Self-Determination, Curriculum, Technology, and Transition
Interest Area: Transition Strand
Mary Held, Karen Thomas

The Work Incentive Transition Network: SSI and Transition Age Youth
Interest Area: Employment Strand
Sheila Fesko, Ellie Emanuel, Helena Hoas, John Butterworth, Vicki Brooke, William Halloran

Spirituality, Bioethics & Disabilities
Interest Area: Spirituality Strand
William Bueche

Natural Supports in the Work: National Studies of Organizational Practices
Interest area: Employment and Transition
David Mank, Patricia Rogan, Becky Banks

Friday, December 10, 1999 1:30 PM - 2:30 PM

Civil Rights and the Media: Getting the Story Right
Interest Area: Governmental Affiars Strand
Michael Reynolds, Jill Jacobs

Mixed Voices: A Training Program on Inclusion for Board Participation
Interest Area: Advocacy Strand
Donna Lowary

The Role of the Family Advisor in Supporting Parents in Obtaining Inclusive Education
Interest Area: Inclusive Education
Judith Terle, Beth Wanger

Partner Power: The Next Generation
Interest Area: Advocacy Strand
Jopie Smith

Functional Assessment with Parents to Increase their Children's Social Communication
Interest Area: Early Childhood Strand
Mark Larson

Friendship on the Electronic Playground: Observations of Inclusive Computer Play
Interest Area: Leisure and Recreation
Tim Hobbs, Cheryl Astolfi, John Sanko, Lori Bruch, Sally McCullon

Finding Identity in Children's Literature: Voices & Culture Images
Interest Area: Inclusive Education
Valerie Owen, Junko Yokota

WANTED: Two Million Teachers
Interest Area: Professional Development Strand
Janice Payne, Charles Fitzgerald

Self-Determination: Scott's Perspective on Working and All That Jazz
Interest Area: Self-Determination
Christine Bevilacqua, Jacqueline Fowler, Scott Fowler, Walter Fowler

Partnerships Make Self-Determination Work: A Model in New York State
Interest Area: Self-Determination
Trudy Fletcher, Clint Perrin, Janet Austin, Steve Holmes

Unifying General Education & Special Education Resources to Support All Students
Interest Area: Inlcusive Education
Pam Hunt, Annette Jenkins, Brian Chapman, Darlene Hardin, Judy Alexander, Pat Saddler, Phoebe Diamond

Cooperative Learning and Inclusion: Learning and Playing Together
Interest Area: Inclusive Education
Mara Sapon-Shevin

Legal and Educational Responsibilities of Schools for the Provision of Health Care Services
Interest Area: Special Health Care Needs Strand
Donna Lehr, Jill Greene

Rural-Urban Whole Schooling Research Project
Interest Area: Research
Kim Beloin, Holly Feen, J. Michael Peterson, Joanne Suomi, Paula DeHart, Rich Gibson

Welcome to Our Home: Individualized Housing Alternatives in New York State
Interest Area: Independent Living
Laurie James, Karen Bradley, Martha O'Grady, Sanrose Shaw

Life in the General Education Classroom: Type & Degree of Participation
Interest Area: Inclusive Education
Sandra Alper, Martin Agran

Making Self-Determination Real: Stomping Out Barriers
Interest Area: Self-Determination
B.J. Bertrand

The Myth of Science in Social Science: Exemplifying Facilitated Communication
Interest Area: Communication
Don Cardinal

Linking Outcomes Based Teacher Preparation to the Portfolio Assessment Process
Interest Area: Personnel Preparation
Mary Beth Doyle

Creating & Supporting Systemic Change in Urban Schools
Interest Area: Urban Strand
Ellen Rice, Deborah McKnight, Janette Hernandez

Wills and Trusts
Interest Area: Guardianship Strand
Joel Wellber, Dohn Hoyle, Patricia E. Dudek

Is the ADA Still Good Law? And How is it Being Used in the Criminal Justice System?
Interest Area: Criminal Justice Strand
Barbara Ransom, Frank Laski

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Teaching Social Skills in Collaboration with Families
Interest Area: Autism Strand
Cathy Apfel, Beth Dixon, Rae Sonnenmeier

RSA Choice Grants - Lessons Learned
Interest Area: Self-Determination Strand
Hank Bersani, Michael Callahan

Friday, December 10, 1999 1:30 PM - 3:45 PM

Pathfinders: School to Community Life — ala New York City
Interest Area: Transition Strand
Fredda Rosen, Beth Mount Carolann Granata, Connie Lyle O'Brien, Debbie La Mothe

Legislator's and Parent's Forum
Interest Area: Family Strand
JoAnn Herzberger, Dennis Hastert, Henry Hyde, Peter Fitzgerald, Richard Durbin

Bigger is Better: Mediating Challenging Behavior Through Social Supports
Interest Area: Positive Approaches Strand
Kimberly Smalley, Cindi Avanzino

The Needs and Strengths of Families
Interest Area: Family Strand
Bob Manwaring, Janet Forbes, Zana Marie Lutfiyya

Transforming Community through Creative Arts and Theater
Interest Area: Creative/Performing Arts Strand
Amy Roth, Emily Anderson

A Little Session on Person Centered Planning
Interest Area: Community Living Strand
Marsha Forest, Jack Pearpoint, John O'Brien

Friday, December 10, 1999 2:45 PM - 3:45 PM

What's Really Happening in the Community? Second Generation Problems in Rural Maine and Urban Louisiana
Interest Area: Management
James Meehan, Gail Fanjoy, Jeffrey L. Strully

Advance Directives: Peril & Promise
Interest Area: Ethics/Rights
Rita Marker

Self-Determination - The Michigan Experience
Interest Area: Self-Determination Strand
Sylvia Kloc, Cheryl Polite, Kristine Copeland, Michael J Head

Setting up a Deaf Education Program in Public School
Interest Area: Inclusive Education
Ann Scheriff

Journey of a Lifetime...Beginnig with the End in Mind
Interest Area: Early Childhood Strand
Karen Gaffney

Membership Revitalized in a Voluntary Association
Interest Area: Advocacy Strand
Rick Tutt

Demonstrating the Co-Teaching Model in Action in an Urban Multi-Cultural Education Setting
Interest Area: Urban Strand
Mark Doyle, Peter Zimmerman

Including Students with Asperger's Syndrome: A Workshop for Elementary Teachers
Interest Area: Inclusive Education
Russell Johnston

Lessons in Transition Partnerships: An Innovative School District/University Relationship
Interest Area: Transition Strand
Dawn Hunter, Jan Mower

Teacher Preparation: Strategies to Promote Successful Inclusion
Interest Area: Professional Development Strand
Gay Culverhouse

Open Hearts, Open Minds, Open Doors: Inclusion in Faith Communities
Interest Area: Religion/Faith Strand
Joanne Meyer

Integration in Employment Settings: Implementation and Research Issues
Interest Area: Employment Strand
Keith Storey, Denise Mautz, Teresa A. Grossi

Emerging Practice in Consumer Contracts to Maximize Choice and Authority
Maximize Choice and
Interest Area: Self-Determination
Roy Gerstenberger, Mark Mills

You're a What? The Role of the Inclusion Facilitator at Elementary and Middle School
Interest Area: Inclusive Education
Pokey Bolton, Patricia McDaid

Self-Regulation Strategies
Interest Area: Autism Strand
Cathy Apfel, Rae Sonnenmeier

Friday, December 10, 1999 2:45 PM - 5:00 PM

Nothing About Me Without
Interest Area: Advocacy
Michael Bailey, Cindy Helvington, Jill Flynn, Judy Cunio

The Last Resort: Hitting Home Runs in Due Process
Interest Area: Advocacy Strand
Mark Partin, Linda Rammler

The Pennsylvania System of Alternate Assessment
Interest Area: Inclusive Education
Steven Lyon, Donna Lehr, Elisabeth Healey, Naomi Zigmond

Ways of Constructing Lives and Disabilities: The Case for Open Inquiry
Interest Area: Research
Scot Danforth, Ellen Brantlinger, Lous Heshusius, Phil Ferguson, Steven Taylor

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Statewide Alternate Assessment: IEP Objectives Drive Portfolio Evidence &
Interest Area: Personnel Preparation
Sarah Kennedy, Michael Burdge

Using Video: Creating Culture, Breaking Barriers,
Interest Area: Self-Determination
Ryan Geake, Debbie Reid

Preserving Families: Keeping Medically Fragile Children in their Communities
Interest Area: Special Health Care Needs Strand
Arlene Lockenwitz, Eileen Lee, Kathy Ryan, Patricia Luce, Trina Bingham

Honoring the Journey: The Spiritual Dimensions of Person-Centered Planning
Interest Area: Spirituality Strand
Craig Michaels, Denise Ferrara

Guardianship Crackerbarrel
Interest Area: Guardianship Strand
Mayer Shevin

Crackerbarrel on Policy Issues in Supported Employment and Transition
Interest Area: Employment Strand
Mike Callahan

Responding to Trauma in Adults with Developmental Disabilities
Interest Area: Criminal Justice Strand
Terri Pease

Creating Creativity
Interest Area: Management
John Irvin

Friday, December 10, 1999 4:00 PM - 5:00 PM

Planning for the Future of Your Child
Interest Area: Advocacy
Nadine Vogel

Bridging the Gap between Special Education & Vocational Rehabilitation
Interest Area: Transition Strand
Laura Owens-Johnson, Sarah Johnston

Why Not Have a Job? The ABC's of the Workforce
Interest Area: Employment Strand
Joseph Pichler

The Dynamic Building of Family Involvement into Best Practices
Interest Area: Family
Susan Catlett, Mary Lasater

Supporting Students with Autism Spectrum Disorders in General Education Settings
Interest Area: Strand on Students Who Severely Challenge Schools
Cathy Pratt, Margaret Lang

Self-Determination: Are we Meeting the Needs of Diverse Learners?
Interest Area: Self-Determination Strand
Colleen Thoma, Douglas Fisher, Mary Givens

Included Students = Isolated Parents?
Interest Area: Inclusive Education
Lynne Tamor, Shari Krishnan

Utilizing Arts Activities to Teach Disability Awareness
Interest Area: Creative and Performing Arts
Heather Downey

The Education of Eugene Marcus: Jowonio means to Set Free
Interest Area: Autism Strand
David Marcus, Eugene Marcus

Social Interaction & Peer Acceptance in Inclusive Classrooms: Maximizing Social Benefits
Interest Area: Inclusive Education
Keli Mu, Ellin Siegel-Causey

How to be an Involved Parent without being Used, Abused and Burned Out
Interest Area: Family Strand
Rhonda Best

Advocacy-in-Action: Strategies for Building Active Grassroots Support & Alliances
Interest Area: Advocacy Strand
Rebecca Salon, Germaine Payne, Luctus Mangru, Jr., Phyllis Holton, Ricardo Thornton, Robert Kennedy, Jr.

Searching for Success During Transition: Developing Success Identities among Urban Adolescents
Interest Area: Transition Strand
Sarah Johnston-Rodriguez

Indexing Community Risk for Treatment of Sexual Deviance
Interest Area: Criminal Justice
Karl Pfeiffer, Karen Ward

Teaching Collaborative Negotiation Skills to People with Disabilities & Others in their Lives
Interest Area: Self-Determination
Dave Black, Jackie Henderson, Lyle T. Romer, Michael Etzell

Social Reinforcement & Environmental Modifications as Sole Elements in Behavioral Intervention
Interest Area: Positive Approaches Strand
Frank Marone, Teresa Gallegos

Picturing Change: The Use of Case Studies for Inclusive Teacher Preparation
Interest Area: Professional Development Strand
Mary Fisher, Debbie Staub, Jennifer J. Coots, Marquita , Stacey Minondo,

Judith Snow: 50th Birthday Celebration
Interest Area: Community Living Strand
Marsha Forest, Jack Pearpoint, John W. O'Brien, Judith Snow

Ideology & "Best Practices" for Young Children Labeled with Autism
Interest Area: Early Childhood Strand
Alicia Broderick

Team Teaching in an Inclusive Setting: Four Key Areas that Can Make the Difference
Interest Area: Urban Strand
Karren Ray, Edward Patock

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— Friday Poster Sessions —

Friday
Poster Session III
12:15 - 2:30 PM

Effective Paraprofessional Programs
Interest Area: Paraprofessional
Diana Johnson

Identifying Instructional Strategies that Increase Choice-Making, Independence, & Self-Determination
Interest Area: Self-Determination
Edward Grasso

Empowerment from Within: How to Develop a Mentoring Program in Your Agency that Really Works!
Interest Area: Personnel Preparation
Terrence Clinkscales, Martin Cottman, Christina Bachman, Michelle Sparling

Use of Within-Activity Choices to Reduce Children's Challenging Behavior
Interest Area: Students Who Severely Challenge Schools
Christine Cole, Tara Skibitsky

Transition of Students with Severe Disabilities from Elementary to Middle School
Interest Area: Inclusive Education
Paula Nargi

Tri-State Consortium on Positive Behavior Support
Interest Area: Positive Approaches
Tim P. Knoster, Jeannine Brinkley, Don Kincaid, Carol Schall

Teaching and Learning for Inclusive Schools in New Zealand
Interest Area: International Inclusion
Jova Carter

Providing Transitional Psychosocial Rehab Services to Young Adults w/ Emotional Disturbances
Interest Area: Transition
Kate R. Donegan, Harry Carson

Prevention & Intervention in Sexual Abuse/Assult w/ Persons with Significant Disabilities
Interest Area: Sexuality
Melissa Darrow Engleman, Malatka King-Albrecht

Intervention for Severe Behavior Problems in an Inclusive Setting
Interest Area: Positive Approaches
Stephanie Peck, Barbara Nicolai

Louisiana's Self-Determination Research Project
Interest Area: Self-Determination
Dalun Zhang

Will I be Alone When I Graduate from School?
Interest Area: Transition/Research
Hyun-Sook Park

Friday
Poster Session IV
2:45 PM- 5:00 PM

Using Technology to Promote Collaboration in Preservice Programs
Interest Area: Personnel Preparation
Janis Chadsey, Suzanne Lee

How Teacher Education Standards Challenge Social Justice & Diversity
Interest Area: Personnel Preparation
Valerie Owen, Terry Smith, Paula Neville

Including All Children in Kindergarten through Collaborative Transition Planning
Interest Area: Inclusive Education
Jane Ross-Allen, Wayne Fox

Global Connections
Interest Area: Multicultural
Mary B. Stauffer, Vasu Babu

The Philadelphia Inclusion Network: Welcoming All Children
Interest Area: Early Childhood
Lillian M. McCuen

Effects of Increased Choice Opportunities on Staff-Initiated vs. Self-Initiated Behavior
Interest Area: Self-Determination
Lillian Staten

Community Calendar Planning
Interest Area: Leisure and Recreation
Teresa Callahan

Video Self-Modeling
Interest Area: Self-Determination
Beverly Tallman

Barter, Borrow, and Budget: Creative Approaches to Community Participation
Interest Area: Research
Joanna Royce-Davis

Inward-Bound — for the Mothers of Children with Significant Disabilities
Interest Area: Family
Margaret Stout, Barbara Simon

1999 TASH CONFERENCE EXHIBITS

The TASH Conference promises to be *the* place to host over 2,500 of your customers! Each exhibitor will receive three conference registrations, a complete booth package, TASH discounted hotel and airline rates, and the opportunity to capture an audience interested in the innovative services, products, and information available to assist people with disabilities from around the world. And we are offering a new value-added feature to the exhibitor package this year: your company name, booth number, and a list of up to five products or services on TASH's web site at no extra cost!

Plan to join us in the Exhibit Hall for our Grand Opening Reception on Wednesday, December 8, 1999 from 5:00 PM to 7:00 PM.

The Exhibit Hall will be filled with exhibits of the products, publications and services TASH conference attendees are looking for. There will be drawings for exciting door prizes in the Exhibit Hall each day of the conference. We welcome back many vendors familiar to our attendees, and we are pleased to have many newcomers joining us in Chicago. Plan to do your holiday shopping with us!

Some of the many exhibitors to be seen at the 1999 TASH conference include:

- Attainment Company
- Aurora Ministries
- Autism National Committee Bookstore & Herb Lovett Foundation
- Brookes Publishing Company
- Human Policy Press, Center on Human Policy
- Diverse City Press
- DynaVox Systems
- Global Ideas, Inc.
- Inclusion Press
- International Rett Syndrome Association
- Issues in Developmental Disabilities (University of Wisconsin-Madison)
- Life Planning Services
- LMD, The Special Kid Company
- Moving Solutions
- *National-Louis University (Official Sponsor)
- Peak Parent Center
- Project RSVP: Birch and Davis
- Special Needs Project
- Super Duper Publications
- *The Chicago Mayor's Office for People with Disabilities (Official Sponsor)
- The Council on Quality and Leadership
- The Nth Degree
- Trips, Inc
- *William M. Mercer, Inc. (Official Sponsor)

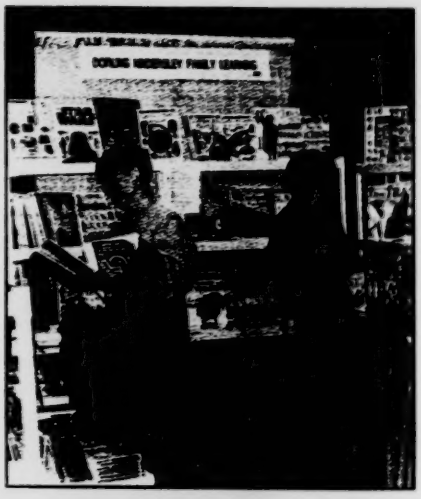
Added exhibit features to maximize traffic in the Exhibit Hall:

- *Exclusive* exhibit time each day of the conference
- Conference Registration and Information areas located in the Exhibit Hall
- Opportunities for exhibitors to display, discuss or demonstrate products to conference attendees in the Special Presentation Area
- Food service in the Exhibit Hall
- Poster Sessions and Special Speakers Area held in the Exhibit Hall throughout the conference

Exhibit Schedule

- **Exhibit Set-Up:**
  Wednesday, December 8, 1999
  12:00 PM - 5:00 PM
- **Opening Reception:**
  Wednesday, December 8, 1999
  5:00 PM - 7:00 PM*
- **Exhibit Hours:**
  Thursday, December 9, 1999
  7:30 AM - 9:00 AM*
  11:00 PM - 6:00 PM
  Friday, December 10, 1999
  7:30 AM - 10:30 AM
  1:00 PM - 7:00 PM
  (5:30 PM - 7:00 PM*)
  Saturday, December 11, 1999
  7:30 AM - 12:00 PM
  (7:30 AM - 8:00 AM*)
- **Exhibit Breakdown:**
  Saturday, December 11, 1999
  12:00 PM - 5:00 PM

**Exclusive Exhibit Hours*



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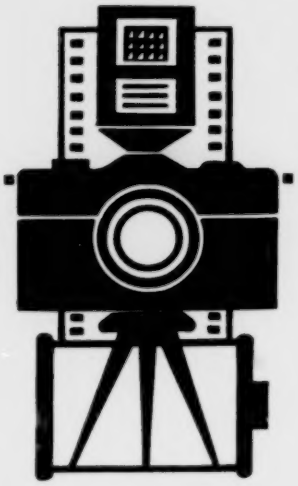

Be Seen at the TASH Media Festival!

Do you have a fantastic video that you'd like to market to the TASH audience? A video that depicts inclusive lives and experiences of people with disabilities; instructs parents or professionals who support people with disabilities; demonstrates school and community inclusion; or addresses specific training needs or current issues? If so, now is the time to take advantage of the opportunity to show your video to over 2,500 TASH conference attendees.

The TASH conference attracts an incredibly diverse group of people with disabilities, parents, advocates, administrators, educators, professional, and community members who are all concerned with rights, equity, and full participation in the lives of people with disabilities.

For only $119.00 per video, we will show your film in the TASH Media Festival, ***and*** give you a ***free*** 1/4 page ad in the conference program ***free***.

Saturday, December 11, 1999 8:00 AM - 9:00 AM

Success for All Students: Supporting Parents and Teachers
Interest Area: Inclusive Education
Pam Dillion, Candee Basford, Cathy Heizman, Martin Oppenheimer, Robert Snyder

Advocacy - A Life Experience
Interest Area: Advocacy Strand
John Russ, Jonathan Ellis

The Mentoring Project: Virtual Problem Solving for Special Education
Interest Area: Professional Development Strand
Tim Hobbs, Lee Sebastiani, Tony Russo

Creating an Army for Self-Determination
Interest Area: Self-Determination Strand
Clint Perrin, Chester Finn, Steve Holmes, Tony Phillips

Stories to Inclusion: An Evolution to Success
Interest Area: Urban Strand
Benjamin Walker, Kathy Chapman

Standards: Creating Curricular Expectations
Interest Area: Standards & Assessment Strand
Nancy Frey, Douglas Fisher

Changing to Collaborative Service Delivery for Students with Learning Disabilities
Interest Area: Inclusive Education
Amy Donnelly, Paul Rhodes, Sandy Burton

The Wilbarger Technique in the Classroom
Interest Area: Research
Samantha Bortz

From Emergent to Conventional Literacy Using Dynamic Display AAC Systems
Interest Area: Inclusive Education
Amy Staples, Leonore

Saturday, December 11, 1999 8:00 AM - 10:15 AM

Embracing Our Purpose: A Spiritual Look
Interest Area: Spirituality Strand
Kathryn O'Connell

Whatever it Takes: From Family Support to Self Determination
Interest Area: Family Strand
Marilyn Kuna

Literacy Instruction for Individuals with Severe Disabilities: Linking Language, Literacy and Life
Interest Area: Inclusive Education
Susan DeLuke

Community Living - Community Relationships
Interest Area: Community Living Strand
Denise Neushwander-Frink, Sandy Zeidler

Inclusion is More Than 10 Easy Steps
Interest Area: Inclusive Education
Nicole Straight

Providing Positive Behavior & Community Based Supports to Youth with Autism
Interest Area: Positive Approaches Strand
Sara Woolf, Laurel Ross

Teamwork for Students with Inclusive Placements
Interest Area: Transition Strand
Naomi Law, Carolyn Effgen, David Effgen, Maureen Pyne, Patrick Schwarz, Valerie Barnes

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Saturday, December 11, 1999 9:15 AM - 10:15 AM

A Teacher's Guide to Communicating with Students who Experience Deaf-Blindness
Interest Area: Communication
Melissa Engleman, Harold Griffin, Linda Griffin

Creating Inclusive Communities through Children's Literature
Interest Area: Inclusive Education
Mary Fitzgerald, Kate Wilson

Classrooms for All: High Standards, Accountability and Inclusive Practice
Interest Area: Standards & Assessment Strand
Maria Timberlake, Betsy Enright

Three High Schools' Experiences Developing Inclusive Practices
Interest Area: High School Inclusive Education
Steven Lyon, Becky Knickelbein

Community Inclusion for Children with Disabilities
Interest Area: Leisure and Recreation
Ellen Fennick, James G. Royle

From Dreams to Reality
Interest Area: Self-Determination
Paul Selby

Community Services for People with Inappropriate or Deviant Sexual Behaviors
Interest Area: Criminal Justice
Karl Pfeiffer, Karen Ward

Individualizing Education for Students with Autism: Research on Two Models
Interest Area: Research
Diane Browder

An Interview with Siblings of Children with Autism
Interest Area: Family Strand
Kathryn Peckham-Hardin

Making Funds Follow Philosophy: The Art of Rightious Spending
Interest Area: Self-Determination
Norm Davis, Bill Allaire, Roger Deshaies

Show Me the Money: Consumer Directed Services Supporting Self-Determination
Interest Area: Self-Determination Strand
Leslie Boggis, Gloria Zela

Professional Development Can Be Fun
Interest Area: Professional Development Strand
Stacy Minondo

Community Self-Employment Loan Fund: Empowerment & Self-Employment
Interest Area: Employment Strand
Wayland Roberts, Jeanne Neath, Kay Schriner

Chronicles of Administrative Leadership Toward Inclusive Education
Interest Area: Urban Strand
Alice Udvari-Solner, Maureen Keyes

Self-Advocate Perspective on Guardianship
Interest Area: Self-Determination
Gayle Gardner

Managing in an Era of Consumer Empowerment - Management
Interest Area: Advocacy Strand
Max Chmura, Marti Romero-Mitchell , Patty Veselsky

Page Five of Daily Life of a Person with a Disability
Interest Area: Independent Living
Roberta Hoffman

The Board Resource Center
Interest Area: Management Issues
Sherry Beamer, Markus Starford

Saturday, December 11, 1999 9:15 AM - 11:30 AM

A Comprehensive Approach to Supporting Individuals with Challenging Behaviors
Interest area: Positive approaches
Paul White, Chris Heimeri

The RRTC-PBS: Research on Durable Lifestyle Support
Interest Area: Research
Glen Dunlap, Anne Todd, Bobbie J. Vaughn, Daniel Baker, Hank Edmonson, Jared Warren, Lise Fox, Richard Albi, Rob Horner, Steve Newton, Yu-Ching Hsiao

Reaching My Own Greatness: An Interactive Training on Self-Determination
Interest Area: Self-Determination
Donna Lowary

We're People First
Interest Area: Creative and Performing Arts
Jeff Moyer

Effectively Managing Support Staff
Interest Area: Management
Denise Mautz

Students with Disabilities and College: A Crackerbarrel Discussion
Interest Area: Inclusive College Education
Lou Brown, Elisabeth Healey, Ian Pumpian, Lynne Sommerstein, Rita Rubin, Susan Rubin

Saturday, December 11, 1999 10:30 AM - 11:30 AM

Everyone Comes to the Table: An Inclusive Secondary
Interest Area: High School Inclusive Education
Anne Bauer, Jan Rich, Karen Matuszek, Mary E. Ulrich

The Relationship Between Functional Behavioral Assessment & Manifestation Determination
Interest Area: Positive Approaches Strand
Tim Knoster

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In Junior High You Take Earth Science: Practical Inclusion Strategies
Interest Area: Inclusive Education
Ellin Siegel, Carol McMorris

Evaluating Your Professional Development
Interest Area: Professional Development Strand
Mary Lasater

Training Former Institution Staff in Person-Centered Values
Interest Area: Community Living Strand
Angela Novak-Amado, Michael R. Fitzgerald

Let's Tango...The Dance of Self-Discovery
Interest Area: Management
Katherine Carol

Exploring "Leisure Time" of Adults with Moderate or Severe Disabilities
Interest Area: Leisure and Recreation
Margaret Hutchins, Adelle Renzaglia

Conversion to Supported Employment
Interest Area: Employment Strand
Danielle Thuot, Rita Thuot, Tonda Stillwell

Discovering the Essence of Human Beings through Active Listening
Interest Area: Multicultural
Roy Scheller

Inclusive Education & Self-Determination: It's More Than Skills Development
Interest Area: Self-Determination Strand
Mary-Ellen Fortini, Jacqueline Thousand

Proven Winners: Successful No Cost Ideas to Begin or Expand Inclusive Services
Interest Area: Management
James Meehan, Gail Fanjoy

Not Able to Exhibit This Year?

You can still reach the TASH Audience!

If you are unable to have a booth in the TASH exhibit hall this year, but would like to take advantage of the opportunity to have your books, videos, brochures, catalogs, or pamphlets distributed or displayed to TASH Conference attendees, then this offer is for you!

Brochures announcing new publications, videotapes, conferences and workshops, or books which are targeted to parents, advocates, professionals, educators, community service providers, or anyone attending the conference are welcome. For $119.00 we will display your product in the exhibit hall!

If you would like an application to be part of the Display Table, please contact the TASH Central Office at 1-800-482-8274.

Teaming Within and Across Schools: Moving Toward a Collaborative Teacher Preparation Program
Interest Area: Paraprofessional
Mary Fisher, Deborah Taub

Tightrope Walking Without A Net: Discrepancies between the Vision & Practice of Inclusion
Interest Area: Inclusive Education
Sue Hamre-Nietupski, Ann McKee

Creating Links Between Preservice & Inservice Teachers via Technical Assistance
Interest Area: Personnel Preparation
Mary Beth Doyle

Saturday, December 11, 1999
10:30 AM - 12:45 PM

Making Links: The Internet and Self-Advocates
Interest Area: Advocacy Strand
Rachael Zubal, Loraine Luterbach, Mair Hall, Sandra Cormier, Shelley Trigg

Effective Parent Advocacy and Forming Effective Parent Advocacy Groups
Interest Area: Advocacy
Marie Sherrett

Opening Doors and Creating Learning Opportunities
Interest Area: Urban Strand
Cheryl Crosby

Practical Ways to Assess and Teach Pre-Language Communication Skills
Interest Area: Communication
Vicki Gerrits, Bonnie McLellan, Deb Buckingham, Kathy Gilman, Linda Wiger, Sarah Pitzner

An Agreement to Partner-K/resa Consortium and Michigan Rehabilitation
Interest Area: Transition Strand
Beth Steenwyk, Cherrie Stoltzner, Laurel Jefsen

Good Grief! Basic Stages of Grief
Interest Area: Family Strand
Kathy Kaluza Morris, Guy Morris

Flexible Service Delivery: Meeting the Needs of Diverse Learners
Interest Area: Inclusive Education
Kathryn Cox, Diane Morrison, Greg Alota, Mary O'Brian, Richard Swastek

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Engineering Environments to Support Augmented Communication
Interest Area: Family Strand
Suzanne Sawka, Christopher Sawka, Josh Harris, Pamela J. Harris

Alternative Assessment: Ideas for Teachers and Parents
Interest Area: Standards & Assessment Strand
Jacqui Kearns, Amy Wildman, Jean Clayton, Kim Costello, Michael Burdge

Self-Determination and the Right to Communicate
Interest Area: Communication
Pascal Cravedi-Cheng, Harvey Lavoy

Spirituality in the Lives of Principals & Teachers
Interest Area: Spirituality Strand
Mary Hickey

Saturday, December 11, 1999 11:45 AM - 12:45 PM

New Strategies for Learning
Interest Area: Inclusive Education
Rita Skiles, Jerry Gronewold

Strategies for Educating Students, ages 18-21, on Post-secondary Campuses
Interest Area: Inclusive Education
Christine Templet, William Sharpton

A Functional Approach to the Design of Proactive Interventions for Students with Challenging Behaviors
Interest Area: Positive Approaches Strand
Jan Writer

Delaware Alternate Portfolio Assessment: Implementation Studies
Interest Area: Alternate Assessment
Mary Ann Mieczkowski, KelliAnderson, Shaunna Crossen, Suzanne Landmesser

Inclusive Education in the 90's- One School District's Perspective
Interest Area: Inclusive Education
Phil Vedovatti, Barbara Toney, Carol Auer, Jacqueline J. Vivoli, Melanie Dixon

Club TASH 1999

Once again this year we will be partnering with KiddieCorp to bring you the quality Child Care/Club TASH at the 1999 TASH Conference that you have enjoyed in the past few years. Space is on a first come first serve basis. On the next page you will find an application to participate in the program, which must be received no later than November 15, 1999.

Please include brief information about your child on the back of the form, including any special interests of your child, medical needs, or accommodations required. More complete history information will be requested at a later date, however this will assist us in preparing safe, and enriching programs.

- Club TASH is designed for infants through age 12. Applicability after age 12 will be determined on an individual basis.
- Childcare will be provided by KiddieCorp, which is licensed and bonded to provide quality care. In addition to the staff provided by the company, TASH members and conference registrants volunteer to assist in Club TASH, making the child to adult ratio very low.
- Childcare will be located at the Chicago Hilton and Towers, which is the headquarter hotel for the conference. Caregivers will be provided with a beeper to wear during the hours your child is participating in Club TASH. This will be at no additional cost, however, to protect against loss, you will be required to put a deposit on the beeper.
- A full schedule of activities geared to the children who are participating in the program will be provided. All activities take place on-site. A schedule of activities can be provided closer to the conference dates.
- Snacks are provided, however parents must make arrangements for lunch. You can pack a lunch, take your child out to lunch, or make arrangements with the daycare provider to order lunch through the hotel.
- Please arrive early the first day to allow ample time for any necessary paperwork and/or discussion with the staff. Childcare opens at 7:45 each day, except Wednesday, which opens at 8:00.
- You may sign up for partial days, however there is a three hour minimum.

You will receive more information with your confirmation letter and release forms once payment is received. If you have any further questions, please contact Denise Marshall, 410-828-8274 x103 or dmarsh@tash.org

Self-Determination: What do teachers know and how do they learn it?
Interest Area: Self-Determination
Colleen Thoma, Michael Wehmeyer, Paul Selby

Leadership Agent Teams: Self-Advocates Serving on Boards
Interest Area: Self-Determination Strand
Shelley Dumas, Anna Escamilla

Spectrum: A Decade Successfully Supporting People who Challenge the System
Interest Area: Community Living Strand
Aaron Johannes, Ernie Baatz, Mary Margaret, Shirley Birtwistle, Susan Kurliak

School Based - University Professional Development
Interest Area: Professional Development Strand
Ellen Rice, Jan Valle

Supporting People, Not Just Their Behaviors
Interest Area: Positive Approaches
Bob Bowen, David Mandt

TASH Child Care Registration Form

Please fill out this form and return to TASH at the address listed below, NO LATER THAN 11/15/99. *MAKE CHECKS PAYABLE TO TASH.* A confirmation letter with release forms will be sent to you once payment is received. **Please send in a paragraph with this form about your childs interest and needs.** Please indicate the age each child will be on December 1, 1999.

CHILD'S NAME_____ AGE:_____ SEX:_____ BIRTHDATE:_____
CHILD'S NAME_____ AGE:_____ SEX:_____ BIRTHDATE:_____
CHILD'S NAME_____ AGE:_____ SEX:_____ BIRTHDATE:_____

Rates are $2.00 per hour per child with a consecutive three hour minimum period required.

Day	Hours of Operation	Specific Hours of Care Requested	Number of Children	TOTAL Per Day
Wednesday 12/8/99	8:00-4:30			$
Thursday 12/9/99	7:45-5:45			$
Friday 12/10/99	7:45-5:45			$
Saturday 12/11/99	7:45-1:00			$
		Non-Refundable Reg. Fee $5.00		$
		GRAND TOTAL		$

*Payment: *Check____ Visa____ Mastercard____ Discover____*

*Card#*_____ *Exp. Date*_____

The Child(ren) named above will be released ONLY to the person(s) signing this application and the following additional person(s):

Father/Guardian Full Name:_____ Signature:_____

Mother/Guardian Full Name:_____ Signature:_____

Address:_____ City:_____ State:_____ Zip:_____

Home Phone#:_____ Daytime Phone#:_____

Mail this completed Registration Form and FULL PAYMENT, payable in U.S. Funds, NO LATER THAN 11/15/99 to TASH 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204.

For Office Use Only
Amt. Recvd._____ Amt. Due_____ On Timeline_____ In Comp._____

TASH Conference Registration

"TASH 2000: Our Turn Now"

Chicago Hilton and Towers • December 8–11th

Mail form to: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore MD 21204 or
Fax form to: TASH, (410) 828-6706
Questions? Call: 1-800-482-TASH (8274)
Email: registration@tash.org
TDD (410) 828-1306
This form can also be found on our website www.tash.org

Agency / Organization / School Information: (if applicable)

Name of Agency/Org/School: _____

❑ This organization is a current TASH Member # _____

Contact Person: _____

Address: _____

_____

City / State: _____ Zip/Postal Code: _____ Country: _____

Is this address the billing address? ❑ Yes ❑ No If no — indicate billing address and contact person with phone # here: _____

_____

Conference Attendee: (Please use a separate form for each person)

First Name: _____ Last Name: _____

❑ I am a current TASH Member # _____ Preferred Badge Name: _____

Mailing Address _____

(if different from above) _____

City / State: _____ Zip/Postal Code: _____ Country _____

This address is ❑ home ❑ work ❑ school ❑ other _____ Please send my confirmation via ❑ email ❑ fax ❑ mail

Work Phone: _____ Home Phone: _____

Fax: _____ E mail: _____

TASH MEMBERSHIP:

❑ I am renewing my membership now Mem. # _____

❑ I am becoming a member now

If you are joining with 3 or more people from the same agency/ organization/school take $20 off each person's individual membership rate (must be in the same envelope)!

New And Renewing Members please select membership type (and add rate on other side) <

	International & Chapter	International Only	Chapter Only
Individual	$103	$88	$33
Associate (for people earning $25,000/yr or less)	$60	$45	$20
Organizational	$230	$200	$70
Lifetime	$1000	N/A	N/A

Attributes (please circle all that apply)

1. Administrator/Adult Services
2. Administrator/Education
3. Administrator/Other
4. Adult Service Provider/Staff
5. Advocate/Friend
6. Behavioral Specialist
7. Case Manager
8. Early Childhood Services
9. Educator/Teacher (K-12)
10. Government Personnel
11. Legal Services Provider
12. OT/PT
13. Parent/Family Member
14. Personal Assistant
15. Professional/Public Policy Advocate
16. Professor/Instructor (College/University)
17. Psychologist
18. Regular Education Teacher/Admin
19. Related Service Provider
20. Self-Advocate
21. Social Worker
22. Speech/Language Pathologist
23. Special Education Teacher
24. Support Specialist
25. Staff Development/Trainer
26. Student (College/University) List ID: _____
27. Supported Employment
28. Other _____

Accessibility and Additional Information Requests

❑ Sign Language Interpreter Please indicate dates and times needed: _____

❑ Please list any accessibility/ ADA accommodation needs: _____

(Please note: information about accessibility at the hotel and surrounding vicinity will be available at the information desk on-site)

❑ Child Care/Youth Activities (Note: you must fill out an application in advance to register. Space is limited)

❑ Roommate Referral Program

❑ I would like a mentor to help me get acquainted with the TASH Conference while I am on-site

❑ I have been at the TASH Conference before and would agree to be a mentor to help others while on-site

CONFERENCE REGISTRATION FORM

1999 TASH Conference Registration Payment Information

(Includes Opening Reception on 12/8/99 and Conference Activities 12/9 -12/11/99)

TASH International Members:		
❑	Individual	$219
❑	Student	$169
❑	Parent (non-professional)	$ 49
❑	Self Advocate	$ 49
❑	One Day Only ❑ Thurs ❑ Fri ❑ Sat	$119
TASH Chapter only or Non-Members:		
❑	Individual	$329
❑	Student	$249
❑	Parent (non-professional)	$ 79
❑	Self Advocate	$ 79
❑	One Day Only ❑ Thurs ❑ Fri ❑ Sat	$169

NEW This Year — selected sessions will be audio-taped! Receive one free selection with your registration.

Enter Applicable Registration → $ _____

Discounts: (only one discount can be applied)

❑ Earlybird Registrations (Must be sent with payment by September 24th) — Subtract $20

❑ Groups of 5 or more registering for full conference (all registrations must be received in the same envelope) — Subtract $20 per registrant

❑ A direct support staff person registering with a self-advocate — Subtract $50 from the staff person's registration

❑ Two or more members of the same school team registering together (ie: a special educator and a regular educator, or a regular educator and a paraeducator) — Subtract $50 per registrant

Enter Applicable Discount Here → $ -( )

After November 12, 1999 registrations will be on-site only and a $40.00 late fee must be added. To ensure that your registration process goes smoothly and to save money we encourage you to register early. If you register on-site you must bring this form and payment or authorized PO with you at time of registration. Enter Late Fee Here → $ _____

Enter Total Conference Registration From Above Boxes Here → $ _____

New This Year — I would like to order the 1999 TASH Conference Yearbook (available in June, 2000) Order with your registration and save $10.00 ~~$35.00~~ $25.00 → $ _____

TASH Tech Pre-conference Workshops (Wednesday, December 8, 1999)

1st Choice: TASH Tech Session # _____

2nd Choice: TASH Tech Session # _____

PLEASE BE SURE TO SPECIFY YOUR CHOICES! (see page # 4)

❑ TASH Member	$65.00	
❑ Non-Member	$85.00	
❑ Self Advocate / Parent (Non-Professional)	$40.00	Enter TASH Tech Fee Here → $ _____
❑ TASH/NADD Symposium	$85.00	Enter Symposium Fee Here → $ _____

TASH Membership Dues from Page 5 $ _____

Less $20.00 for three or more joining as TASH-Members from same Org/Agency/School $ -( )

Enter Total Membership Cost Here → $ _____

Additional donation to support a self advocate to attend the conference ❑ $5 ❑ $10 ❑ $20 ❑ Other $ _____

(add all applicable costs) TOTAL AMOUNT ENCLOSED: $ _____

Payment Terms: Registration will not be accepted without payment by check, official purchase order, or credit card authorization. Please note that payment must be in U.S. Funds only. A $25.00 processing fee will be added to all cancellations, or for purchase orders not paid prior to the conference. No refunds will be given for cancellations after November 12, 1999. $25.00 fee for returned checks or unauthorized charges.

❑ Check Enclosed ❑ Purchase Order / State Voucher no. _____

❑ Visa ❑ MasterCard ❑ Discover Name on Card: _____

Card Number: _____ Exp. Date: _____ Signature: _____

1999 Conference Proposal Reviewers

Many thanks to the following people who spent countless hours reviewing the proposals submitted for this year's conference. We appreciate your time and knowledge, and truly could not accomplish such a mammoth task without you!

Rick Amado
Cathy Apfel
Lynda Atherton
Lynda Baumgardner
Alan Berger
Hank Bersani
Rhonda Best
Wanda Blanchett
Beth Brennan
Lou Brown
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Anne Smith
Lisa Sonneborn
Rae Sonnenmeir
Fred Spooner
Jeff Strully
Carol Tashie
Alice Udvari-Solner
Joe Wykowski

1999 Local Committee

description of thanks

Our thanks to the following people for providing invaluable information about the local area, for recruiting local presenters and volunteers, publishing this event in local media and most importantly for showing such enthusiasm and spirit, both of which will help to make Chicago everyone's kind of town!

Thank you!!

Lynda Atherton
Rhonda Best
Charlotte DesJardins
Theresa Devine
Mark Doyle
Mary Ann Fitzgerald
Jane Glodoski
Pam Harris
Ruth Henning
Maureen Keyes
William Kienzle
Debra Kunz
Janet Ladd
Lannie LeGear
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Cathy Nosbaum
Valerie Owen
Sheila Ramano
Patrick Schwarz
Paul Selby
Mand Segrove
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Holly Taylor
Maureen Wall
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Linda Rammler
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Susie Schaefer
Mary Stauffer
Joseph Wykowski
Lucille Zeph

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TASH NEWSLETTER

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

Priscilla Newton, *Editor*

Executive Board

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Patrick Schwarz
Jacqueline Thousand

MEMBERSHIP INFORMATION

Referred by

Name:_____

Address:_____ City/State/Zip:_____

Telephone: ( ) _____ Fax: ( ) _____ E-mail: _____

Is the above your ❑ work address ❑ home address ❑ other_____

Please Check Appropriate Categories (not more than three):

( ) Administrator/Adult Services
( ) Administrator/Education
( ) Administrator/Other
( ) Adult Service Provider/Staff
( ) Behavior Specialist
( ) Case Manager
( ) Early Childhood Services
( ) Educator/Teacher
( ) Gov. Personnel (Federal, State, Local)
( ) Interested Individual/Advocate/Friend
( ) Legal Services Provider
( ) Occupational/Physical Therapist
( ) Parent/Family Member
( ) Personal Assistant
( ) Professional Public Policy Advocate
( ) Professor/Instructor (College/University)
( ) Psychologist
( ) Regular Education Teacher/Administrator
( ) Related Services Provider
( ) Self-Advocate
( ) Social Worker
( ) Speech/Language Pathologist
( ) Special Education Teacher/Support Specialist
( ) Staff Development/Trainer
( ) Student (College/University)
( ) Supported Employment/Day Personnel
( ) Other

Moving? ***Please notify TASH of your new address.***

General Membership (individual) ..... $88.
Agency/business/university/college/library/school ..... $200.
(allows 3 conference attendees at the member rate)
Self Advocate, Parent, Full Time Student, Direct Careworker/Para professional/Personal Attendant (for whom payment of full fee would present a hardship) ..... $45.
Family (group rate) ..... $136.
Lifetime Member ..... $1000.
Add $10 for postage costs for members in Canada and $25 for members outside the U.S. and Canada.

Funds must be submitted in U.S. dollars and checks must be drawn on a U.S. bank. Add a $20 processing fee if check is not drawn on a U.S. bank. If you would like to charge your membership, please fill in the necessary information:
( ) Mastercard ( ) Visa ( ) Discover

Card Number_____ Expiration Date_____

Signature_____

( ) I would like to spread my payments out.
Enclose 1/3 and you will receive 2 additional invoices at monthly intervals.
If you are applying for a student membership, please provide the following information:

Department_____

College/University_____

Student I.D. Number_____

Anticipated year of completion_____

( ) Include an additional $15 if you are applying for an individual membership or $30 if you are applying for an organizational membership and also want to become a member of your local chapter.

Please make check payable to TASH
Address: 29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204
Telephone:410/828-8274 Fax: 410/828-6706

TASH
29 West Susquehanna Avenue
Suite 210
Baltimore, MD 21204
Phone: 410/828-8274,
FAX: 410/828-6706,
TDD: 410/828-1306
Web site: www.tash.org

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TASH

Newsletter

VOLUME 25 ISSUE NUMBER 5 October ~~MARCH~~ 1999

Accessibility in the U.K.
Human Rights Abuses Against Children in Russia
MULTICULTURAL & INTERNATIONAL PERSPECTIVES
Inclusion in Vietnam
Independent Living Stories from Latin America and Cape Verde

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

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Building communities in which no one is segregated and everyone belongs;

—

Forging new alliances that embrace diversity;

—

Advocating for opportunities and rights;

—

Eradicating injustices and inequities;

—

Supporting research and disseminating knowledge and information;

—

Promoting inclusive education;

—

Supporting progressive legislation and litigation; and,

—

Promoting excellence in services.

From the Executive Director
BY NANCY WEISS

This edition of the *Newsletter* is about international and multicultural issues. TASH is a richly international organization with members from the United States, Canada, Puerto Rico, Guam, the Virgin Islands and thirty-eight other countries around the world.

Recently we have undertaken two important international efforts. The first is an effort undertaken by a group of TASH members who have been meeting by phone for several months to discuss concerns about the conditions in Russian institutions for people with disabilities. This group is planning a trip for a small number of TASH members to meet with family groups in Russia and work on ways to assist them to develop alternatives to a lifetime of institutionalization for their family members. We are seeking funding for an initial trip. Six to eight TASH members will participate in the first trip. The major purpose of this trip will be to meet with family groups in the St. Petersburg region of Russia, begin to establish ways that TASH could be helpful to them and design a plan for future exchanges and activities. The planning group is also working on getting some resource materials and technical assistance devices donated so these can be brought to the family groups in a gesture of good will on the initial visit.

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Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about the 1999 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on governmental affairs, call:** Dan Dotson, Acting Director of Governmental Affairs, at (410) 828-TASH, Ext. 104, e-mail:ddotson@tash.org
- **For information on marketing and promotions, permission and reprints, newsletter submissions and advertising, or publication sales, call:** Priscilla Newton, Director of Marketing and Communications, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the Journal (JASH), call:** Linda Bambara, Editor-in-Chief, at (610) 758-3271, e-mail: LMB1@lehigh.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

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From the Executive Director

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In addition, I have been meeting with representatives of Mental Disability Rights International and Physicians for Human Rights to explore opportunities to work together. We've discussed setting up a meeting among several U.S.-based disability organizations and key players in the international rights movement, including Mental Disability Rights International, Physicians for Human Rights, Human Rights Watch and Amnesty International, to discuss the use of aversive procedures and restraints. Most of these groups focus their attention on situations outside of the U.S.. The purpose of this meeting would be to explore ways that the influence of these international rights organizations could be brought to bear on disability rights issues both within the U.S. and internationally.

No amount of money can make an institution a place people would choose to live or that anyone should have to live.

Mental Disability Rights International and Physicians for Human Rights have been particularly concerned about the conditions in Russian orphanages and institutions (see article on pages 8-10). Eric Rosenthal and Holly Burkhalter, representing these groups, wrote an Op-Ed piece that was published in the *Washington Post* in August calling for the United States to rethink its approach to providing aid to the institutions in Russia. Currently, a bill is pending in Congress that would direct millions of U.S. aid dollars toward expanding and improving Russian institutions rather than toward supporting better alternatives. TASH sent the following letter to the *Washington Post*.to voice our concern:

Letter to the *Washington Post*:

You are to be commended for publishing the article by Holly Burkhalter and Eric Rosenthal (8/4/99)on U.S. aid for Russian orphanages (Please see page 10 of this *Newsletter* for the article). *Children and youth with disabilities in Russia deserve nothing less than their American counterparts — a meaningful life in their home communities, the right to individualized educational supports alongside their non-disabled peers, vocational training opportunities that will lead to real jobs, and the right to participate in the kinds of recreational, community, and civic experiences enjoyed by their peers.*

The U.S. Congress, rather than directing aid toward more humane alternatives, is considering a bill that would direct millions of dollars to make Russian institutions bigger and better. One would think we would have learned from our own mistakes. For decades, the solution to the problem of U.S. institutions that did little more than warehouse people with disabilities was to pour money into them. No amount of money can make an institution a place people would choose to live or that anyone should have to live.

It is sometimes believed that people in the United States don't care about people with disabilities and care even less about people with disabilities in distant countries. The disability rights movement in the U.S. is strong and focused. It embraces people with disabilities around the world. It is hoped that by publicizing this potential misdirection of funds you will have improved the opportunities for Russian children with disabilities to stay with their families, have access to a range of community supports, and to lead lives that are valued and meaningful.

— Nancy Weiss
Nancy Weiss is the Executive Director of TASH, an international disability advocacy organization.

If you are interested in participating in any of the efforts described in this article, please contact me by phone (410-828-8274, ext. 101) or e-mail (nweiss@tash.org).

INTERNATIONAL INCLUSION

at the 1999 TASH Conference

Join Anne Smith and Zuhy Sayeed for the International Inclusive Education Strand on Thursday, December 9, 1999 as they explore dimensions of inclusion/exclusion around the world. The Strand will be structured for interactive discussion. Following brief panel presentations, presenters and participants will respond to focused discussion questions to identify emerging themes around the global inclusive movements as well as to highlight activities in various nations and regions across several continents. The day will end with some strategic networking and discussion about how TASH members can become more actively involved in international inclusive education efforts.

This strand features a panel of dynamic speakers including: Carol Berrigan, Dora Bjarnason, Mary Ann Curulla, Shalini Dave, Rosario Diaz-Greenberg, Sue Hamre-Nietupski, Kenn Jupp, Levan Lim, Mary McNeil, Rhonda Neuhaus, Kala Parasuram Shrikanth, Florence Seah, Susan Sygall, Jacqueline Thousand, Rich Villa, and June Yen Siew Sim.

Inclusion is Happening . . . WHERE?

BY RICH VILLA

We Can't Do Inclusion Here Because:

- we have a set curriculum that "those students" can't keep up with or learn;
- students with disabilities won't pass the assessments required to enter the next grade;
- it will lower the standards and learning outcomes for other students;
- the content at the secondary level is too difficult;
- we don't have the resources;
- the rationale for it is humanitarian, not educational;
- we don't have policies to support inclusive practices;
- we don't have the support of the necessary leaders;
- it isn't mandated by law;
- it won't work;
- we don't have time to collaborate;
- it won't meet the needs of students who are....

Sound familiar? I am sure that the readers of this article have encountered similar arguments countless times. Were concerns similar to these expressed to me recently in Los Angeles? Louisiana? in a due process hearing in Rhode Island? Yes, I heard them in Los Angeles. Yes, I heard them in Louisiana. Yes, I heard them in Rhode Island. I also heard them recently in Vietnam. And in Vietnam, just as in a growing number of school systems in the United States, despite all of the barriers, thoughtful and creative professionals, parents, and students are collaborating with one another and crafting inclusive educational opportunities. This article will briefly:

- describe the demographics of Vietnam;
- present an overview of the evolution of special education service delivery in that country;
- discuss the varied rationale why inclusive education is gaining momentum in Vietnam; and
- depict the impact of inclusive education on two students and their families.

Significant policy changes...have resulted in the removal...of a national regulation that barred children with disabilities from preschools. ...The Vietnamese Ministry of Education has shifted its position, stating that 90% of children with special educational needs could be educated in regular schools.

Demographics

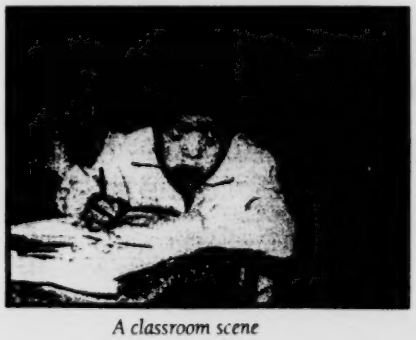
Vietnam has a population of over 76 million, which in terms of population makes it the second largest country in Southeast Asia. Ethnically, Vietnam is the most homogeneous country of Southeast Asia; about 90% of the population are Vietnamese. Life expectancy at birth is 67 years. Vietnam covers an area of 329,600 square kilometers and is 7.5% smaller than reunited Germany. The country extends across two climatic zones and has more than 3,000 kilometers of coastline.

Evolution Of Special Education Service Delivery

The National Institute for Educational Sciences' Center for Special Education (CSE) estimates that there are more than one million children with disabilities in Vietnam. The evolution of services for students with disabilities in Vietnam parallels that of many other countries. The French established the first school for Vietnamese students who were deaf in 1866. In 1975, the year the Education for All Handicapped Students Act was passed by the U.S. Congress, Vietnam initiated the establishment of a special school system. By 1991, Vietnam had established 36 special schools throughout the country.

Vietnam is proud of the fact that in 1991 they were the second nation -- and the first in Asia -- to ratify the United Nations Convention on the Rights of the Child. The convention articulates the following rights of the child:

I. the right to life, survival, and development;
II. the right to health and medical care;
III. the right to a home;
IV. the right to play;
V. the right to protection from economic exploitation;
VI. the right to protection from sexual exploitation;
VII. the right to a full and decent life which promotes self-reliance and active participation in the community; and
VIII. the right to education (equal opportunities to all compulsory primary education).



A classroom scene

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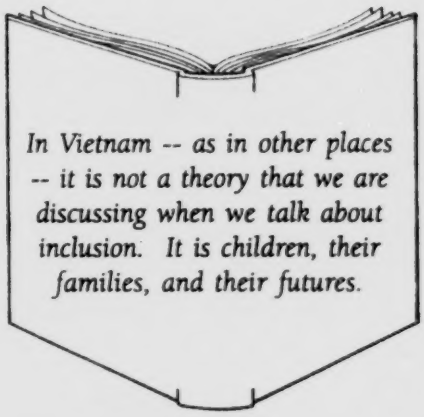
The 1991 legislation enacted by Vietnam included The Law of Protection and Care for Children, which speaks to reintegrating students with disabilities into society, the availability of special schools, and the provision of rehabilitative services. A new Constitution was ratified in 1992 that promotes learning and appropriate vocational training for children with disabilities. When the Center for Special Education (CSE) began to develop training materials to support the integration of students with disabilities in primary schools in 1991, early identification of children with disabilities, support for parents, and inclusion in preschools and secondary schools was rare. It was very unusual for students with significant disabilities to attend neighborhood schools with their non-disabled peers.

Since 1995, CSE has been working collaboratively with Catholic Relief Services (CRS) and other non-governmental agencies (e.g., Radda Barnen) to create inclusive education models. For example, CSE and CRS established inclusive education models in two northern Vietnamese districts, Thuong Tin and Tu Liem, in 1995. The pilot sites were selected as typical rural and urban districts in close proximity to Ha Noi with few pre-existing programs for children with disabilities. I have been providing consultation, technical assistance, and training to CSE, CRS, governmental officials, and educators in Tu Liem, Thuong Tin, and other districts throughout Vietnam since 1996.

During that time, over 800 students with mild, moderate, and significant disabilities have been successfully included in Thuong Tin and Tu Liem. The mid-term evaluation report from CSE/CRS's Thuong Tin and Tu Liem project concluded that training has resulted in a major change in teachers' attitudes toward children with disabilities, as well as a shift from an exclusively didactic approach to group work. A greater sensitivity to students' individual needs by teachers was observed. Additionally, positive changes in the attitude of community members and parents having a more optimistic view of their child's future were also noted.



In Vietnam -- as in other places -- it is not a theory that we are discussing when we talk about inclusion. It is children, their families, and their futures.

Policy changes influenced by the Thuong Tin and Tu Liem projects include: removal of a national regulation in 1997 that barred children with disabilities from pre-schools; a new emphasis by the Vietnamese Ministry of Education stating that "90% of children with special educational needs could be educated in regular schools"; and in 1998, a Vietnamese law was changed so that for the first time students with disabilities had the option of attending special or regular schools.

Today, inclusive education models exist in 51 of the 61 Vietnamese provinces. In contrast, seventy-two special schools and units, located mainly in urban areas, educate or train approximately 4,000 students with disabilities. Those who are "mobile" are often sent to vocational training classes rather than receiving a basic education. So-called "compassionate classrooms" provide daycare instead of regular schooling and most compassionate classrooms consist of children with disabilities, poor orphans, and ethnic minorities.

In September of 1998, CRS and CSE were awarded a four year grant from the United States Agency for International Development (USAID) to expand the successful inclusive educational practices utilized in Thuong Tin and Tu Liem to an additional three districts. The population served and the expected beneficiaries of the grant's activities are described below.

Table 1: U.S.-AID Beneficiaries

Number of Districts	3
Total Number of Communes Per District	60
Population per Commune	7,000 to 9,000
Pre- and Primary School Aged Children	3,000 to 4,000
Estimated Children with Disabilities Per Commune	50
Total Direct Student Beneficiaries	3,000

The project aims to strategically leverage domestic and international experience to strengthen existing support for inclusive education within government and society. At the same time it builds on traditional village values of helping others and empowering local communities and authorities to provide for the educational and social needs of all. The combination of national-level support and local action opens further possibilities for a fully inclusive environment in Vietnam.

In addition, CSE is working to transition students from special schools to community schools while redefining the role of personnel in special schools to function as trainers, technical assistance providers, and consultants. Efforts are underway to pilot changes in the teacher preparation curriculum so that teachers will acquire the skills to educate a more diverse student body.

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Rationale For Inclusive Education In Vietnam

Just as in the United States, varied rationales (e.g., philosophical, international and national law and policy, fiscal, and model demonstration projects) have motivated policy makers, administrators, teachers, persons with disabilities, and others to advocate for the creation of inclusive schools and classrooms in Vietnam. The historical chronology presented above described the international and national policy and laws that have positively impacted the growth of inclusive education in Vietnam. In addition, the power of model demonstration projects that allow policy makers and others to view first hand the implementation of inclusive education has also been described.

In Vietnam, as elsewhere, the journey toward inclusion has begun. The barriers to inclusion are many.... Eternal vigilance is required to maintain the progress that has been made, overcome the barriers, and extend inclusive educational opportunities throughout the country.

Mr. Le Van Tac from the National Center for Special Education describes inclusive education in Vietnam as a process of preparing children and teachers so that those who have been segregated from activities in society can participate in the majority of activities with non-disabled children in the same classroom. Effective inclusion requires community awareness, coordinated community services, teacher and parent training, adapted training methodology, an adjusted curriculum, and low-cost teaching materials. Mr. Tac's visionary leadership has been critical to inclusion education taking hold and growing in Vietnam.

Table 2 compares the cost and capacity of a separate versus an inclusive educational approach to meeting the needs of students with disabilities in Vietnam.

Ho Chi Minh once said, "If you want to benefit in ten years, grow a tree. If you want to benefit in 100 years, grow a child."

Table 2: Cost and Capacity of Separate Versus Inclusive Options

Estimated Children with Disabilities in Vietnam (3% of Total)	Separate Special Education Capacity	Annual Cost Per Child	Districts Implementing Inclusive Education Since 1991	Primary Schools with Inclusive Education Programs	Current Inclusive Education Capacity	Annual Cost* Per Child with Disabilities in Inclusive Education
1,000,000	4,000	$400 U.S.	51	1,000	35,000	$58 U.S.

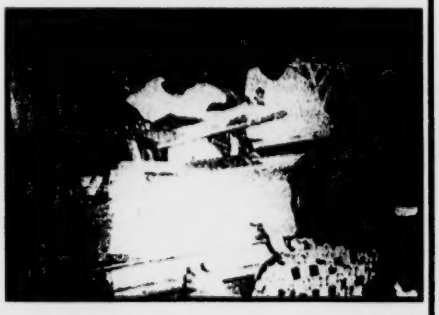
*The annual cost of educating a child without a disability in Vietnam is $20 U.S.

The Face Of Inclusion In Vietnam

In Vietnam, as in other places, it is important to remember that inclusion is about children, their families, and their future. To illustrate this point, I want to briefly discuss two of the many students, Kim and Lum, whom I have met and interacted with during my trips to Vietnam. In essence, I want to conclude this article by putting a face on inclusion in Vietnam.

Kim (seated) and his friends on their way to school.

Kim is a young boy with cerebral palsy. Prior to the implementation of inclusive education, he did not attend school. He was kept at home and viewed as an embarrassment. His grandfather was planning to give him an overdose of sleeping pills. Today, he is in school, has learned to read, and has friends who support him in cooperative groups in school, as well as in getting to and from school.



Kim working with two other students in a cooperative learning group.

Lum is a youngster with cognitive and physical disabilities. When I first met Lum and his family, he was just beginning school. His mother was distraught and overwhelmed by her life circum-

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stances. She explained that both she and her husband had been soldiers during the Vietnam War. Her husband was in poor health. She had given birth to other children in addition to Lum. They had all died. She attributed Lum's disability, the death of her other children, and her husband's poor health to their repeated exposure to Agent Orange during the Vietnam War. As she described her life, loneliness, and fears she began to hit me. At first, I thought it was because I was an American. It was not. She was just overwrought.

Lum at home using parallel bars to walk. The bars were made by members of Lum's community.

The inclusive education program in Thuong Tin created collaborative teams and wrapped support around both Lum and his mother. Today, Lum is successfully included in school and his mother gets respite and support from the other members of her community.

Conclusion

In Vietnam, as elsewhere, the journey toward inclusion has begun. There

Lum (far right, seated on chair) in the classroom.

is much to celebrate and much that remains to be done. Eternal vigilance is required to maintain the progress that has been made and to extend inclusive educational opportunities throughout the country. As an American, it is wonderful to be involved in Vietnam in a productive way. Ho Chi Minh once said, "If you want to benefit in ten years, grow a tree. If you want to benefit in 100 years, grow a child." Today in Vietnam, they have recognized the importance of these words and have begun to create the conditions necessary for all children and youth to grow and flourish in caring and effective schools.

Rich Villa is president of Bayridge Consortium. He provides training and consultation in areas such as collaborative teaming, creative solution-finding, systems change and inclusion. Rich is one of the scheduled keynote speakers at the 1999 TASH Annual Conference.

Rich can be reached by phone: 760-761-4917; or e-mail: 75642.711@compuserve.com

1999 TASH Annual Conference

Special Event

DUE PROCESS STRAND

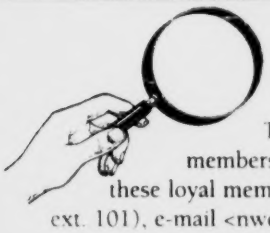
Are you facing the daunting prospects of going through a due process hearing to get a good program for your child? Have you been asked by a parent to be an expert witness and you have no idea what that might involve? Do you want to hear from others who have been through this experience and identify strategies that worked for them?

Gail McGregor and Judy Gran have organized this strand to include sessions that will address these issues and more. As an added support to families, a number of attorneys with expertise in inclusive schooling practices will be available in "consultation rooms" throughout the day of the strand so that families can sign up for a time to meet with an attorney to receive legal advice about issues of concern regarding their child's school program.

This free service is being provided with the support and coordination of the Public Interest Law Center of Philadelphia, and is being offered in conjunction with the Due Process Strand.

Sign up for this great opportunity to get some advice and information about people in your community that can support your efforts to obtain an inclusive educational program for your child.

Thursday, December 9



We're looking for YOU!

TASH is working to identify a list of people who have been members since the organization's inception in 1975. If you are one of these loyal members, please contact Nancy Weiss by phone (410-828-8274, ext. 101), e-mail <nweiss@tash.org>, fax (410-828-6706) or mail (see back cover for TASH's address).

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INTERNATIONAL HUMAN RIGHTS ABUSES AGAINST PEOPLE WITH MENTAL DISABILITIES

BY ERIC ROSENTHAL

There is an enormous need for collaboration between the international human rights and the U.S. disability rights communities. For decades, the international human rights community has seemingly been unconcerned with the issue of people with mental disabilities who are subject to human rights abuses around the world. Most people still associate "human rights" and "mental health" with the political abuse of psychiatry in the former Soviet Union. While major human rights organizations were quick to condemn the Soviet Union for detaining political dissidents in conditions of squalor in psychiatric institutions, the same organizations never held the Soviets responsible for abuses against people with mental disabilities within the same psychiatric facilities.

There is a growing body of evidence that people with mental disabilities are subject to pervasive discrimination and abuse the world over. In the 1970s and 1980s, the United Nations appointed two "special rapporteurs" to document the conditions of people with mental disabilities around the world. They found that, throughout the world, people with mental disabilities were routinely segregated from society in closed psychiatric hospitals, orphanages, or other facilities. Discrimination against people with mental disabilities is common in most societies.

Human Rights Abuses in Latin America and Eastern Europe

Mental Disability Rights International (MDRI) was established in 1992 to promote the inclusion of people with mental disabilities within the international human rights framework. MDRI has investigated human rights abuses against people with mental disabilities in nine countries in Latin America and Central and Eastern Europe, and has published reports on human rights conditions in Uruguay, Hungary, and Russia [Footnote 1]. MDRI's investigations have confirmed the findings of the United Nations special rapporteurs in great detail. Whether it is the "colonias" of Uruguay, the "granjas" of Mexico, the "social care homes" of Hungary, or the psychiatric institutions of Ukraine, people with mental disabilities are all too often rejected by society and left to languish in closed facilities without hope of ever returning to community life.

Over the course of the last few decades, there has been an increasing recognition that people with mental disabilities are, indeed, protected by international human rights law.... We in the disability rights community must work to convince our representatives in Congress that the rights of people with disabilities are, indeed, international human rights issues and as such, are due all of the attention of the more traditional areas of concern. Programs that reflect the recognition of disability rights should be included in the core agenda of our international foreign policy and international development programs.

In Latin America and Eastern Europe, our investigations have found that people detained in closed facilities out of public view are subject to extreme forms of inhumane and degrading treatment, often in dangerous conditions. In psychiatric facilities in Uruguay, we found psychiatric medications used in dangerously high levels and combinations. People with mental retardation are subject to electro-convulsive therapy (ECT) as a form of behavior control.

In Hungary, MDRI documented the detention of people with psychiatric disabilities in caged beds. Individuals detained in these beds, often for months at a time, could not stand up, exercise, or even go to the bathroom. Most of the

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individuals we observed in caged beds were covered in their own feces and many had dangerous bedsores.

Children in Russia's Institutions

In Russia, a vast orphanage system houses 500,000 children. Children with disabilities are labeled "uneducable" and considered "beyond hope." These children are put in "lying down" rooms filled with cribs, where they receive almost no human contact. In parts of the former Soviet Union, we found psychiatric institutions with shortages of food, heat, and basic medications. Mortality rates in these institutions are extremely high.

In addition to documenting human rights abuses, MDRI is committed to training and supporting the development of disability rights advocacy organizations around the world. In almost every country of the world we have visited, we have been pleased to find that people

The development of advocacy movements by and for people with mental disabilities is the key to reform in any country.

with disabilities, family members, progressive mental health professionals, and others, have banded together to work on human rights advocacy and service system reform. Unfortunately, these groups often operate in obscurity. They receive little attention and support within their own society -- or from the international community.

Until recently, disability rights advocacy groups have often worked in total isolation from one another. In the last few years, however, there has been tremendous growth in communication and collaboration among activists from advocacy organizations in the United States, Europe, and Latin America. MDRI has conducted advocacy training programs throughout Central and Eastern Europe to introduce activists from the U.S. movement to their counterparts abroad. Without exception, we have found that activists from different countries face similar challenges and have an enormous amount to share with one another about advocacy strategy.

The development of advocacy movements by and for people with mental disabilities is the key to reform in any country. Veterans of the U.S. movement have 30 years of experience challenging the status quo, and that experience can be critical to individuals struggling in their own countries to establish new advocacy organizations. We must find a way to draw on that experience, to obtain funding for increased exchanges among activists from the United States and abroad, and to leverage the support of international development policies to provide support for the reform in countries abroad.

In recent years, the U.S. Agency for International Development (USAID) and other international development organizations have recognized that support for "civil society" and independent citizen participation is key to bringing about development in any country. U.S. foreign assistance funding has been used to support a broad array of organizations working for human rights, women's rights, children's rights, and the rights of the environment. Funding for disability rights advocacy has been extremely limited. All too often, international programs affecting people with disabilities do not draw on the lessons of the U.S. movement (see related Op-Ed on pages 10-11). People with disabilities, family members, and other concerned activists must play a more active role in

In a landmark case before the Inter-American Commission of Human Rights, an international human rights tribunal found that the United Nations-adopted "Principles for the Protection of Persons with Mental Illness" (the MI Principles) constitute an authoritative interpretation of international human rights conventions as they apply to people with mental disabilities. This greatly increases the importance of the MI Principles as a tool for the protection of people with mental disabilities in the international area.

international program development and implementation. Given the years of past discrimination in the international areas, funds must be specially earmarked for international disability rights work, and disability activists must be brought into foreign assistance programs to spearhead this new effort.

We in the disability rights community must work to convince our representatives in Congress that the rights of people with disabilities are, indeed, international human rights issues and are due the same attention as more traditional areas of concern. Programs that reflect the recognition of disability rights should be included in the core agenda of our international foreign policy and international development programs. As we support countries making the transition to democracy abroad, we must recognize that no democracy is complete when people with disabilities are excluded from every opportunity for full participation in society. Of course, we need to reaffirm the commitment to disability rights in the U.S., so that we may speak free of hypocrisy abroad.

The Development of International Human Rights Law

Over the course of the last few decades, there has been an increasing recognition that people with mental disabilities are, indeed, protected by international

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human rights law. Unfortunately, this recognition was late in coming. Article 1 of the Universal Declaration of Human Rights (UDHR), the cornerstone of the international human rights movement adopted by the United Nations in 1948, promises that "[a]ll human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood." The UDHR prohibits discrimination "without distinction of any kind," but discrimination on the basis of disability is not one of the grounds specifically mentioned.

In April of 1993, there was an important development of international human rights law for people with mental disabilities. In a landmark case in the Inter-American Commission of Human Rights, *Victor Rosario Congo* (Case No. 11.427, decided April 13, 1999), an international human rights tribunal found that the U.N.-adopted "Principles for the Protection of Persons with Mental Illness" (the "MI Principles") constitute an authoritative interpretation of international human rights conventions as they apply to people with mental disabilities. [Footnote 2] The *Congo* case greatly increases the importance of the MI Principles as a tool for the protection of people with mental disabilities in the international arena. It raises new hopes that international human rights conventions will be increasingly used to protect the rights of people with mental disabilities in the future.

In 1971, the United Nations General Assembly adopted the "Declaration on the Rights of Mentally Retarded Persons." In 1991, the U.N. adopted the "Principles for the Protection of Persons with Mental Illness" (the MI Principles), and in 1993, the U.N. adopted the "Standard Rules on Equalization of Opportunities for Persons with Disabilities." These U.N. General Assembly resolutions are important statements of international law, and they set forth a broad array of human rights for people with mental and physical disabilities. Technically they are "non-binding," however, and do not have the status under international law reserved for human rights conventions. Unlike international human rights conventions, there is no United Nations oversight mechanism to ensure that states comply with these general assembly resolutions.

ERIC ROSENTHAL IS THE EXECUTIVE DIRECTOR AND FOUNDER OF MENTAL DISABILITY RIGHTS INTERNATIONAL (MDRI), A HUMAN RIGHTS ORGANIZATION DEVOTED TO THE RECOGNITION AND ENFORCEMENT OF THE RIGHTS OF PEOPLE WITH MENTAL DISABILITIES GLOBALLY.

ERIC CAN BE CONTACTED AT: MDRI, 110 MARYLAND AVENUE, N.E., SUITE 511, WASHINGTON, D.C. 20002; (PHONE) 202-544-6074.

FOOTNOTES:

Footnote 1. See Human Rights and Mental Health: Uruguay (1995); Human Rights and Mental Health: Hungary (1997); Children in Russia's Institutions: Human Rights and Opportunities for Reform (1999). The latter report is on the world wide web at www.MDRI.com. All reports may be obtained by contacting MDRI, 110 Maryland Ave., N.E., Suite 511, Washington, DC 20002.

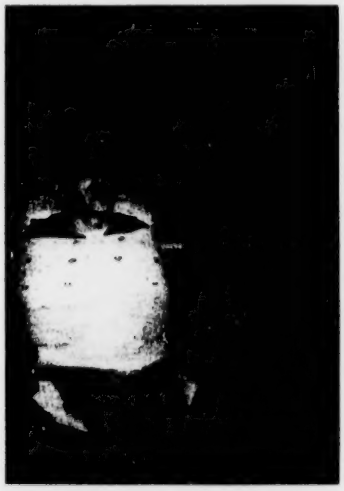
Footnote 2. *Case of Victor Rosario Congo*, p.482, n.4. In its analysis of the need to rely on the MI Principles, the Commission cites Eric Rosenthal and Leonard S. Rubenstein, "International Human Rights Advocacy under the Principles for the Protection of Persons with Mental Illness, 16 International Journal of Law and Psychiatry 257 (1993).

The following Op-Ed piece, published August 4, 1999, Page A21, is reprinted with permission of the Washington Post.

The Way To Save Russia's Orphans

By Holly Burkhalter and Eric Rosenthal

As the Russian economy continues to deteriorate, there are no more riveting images emerging than those of the hungry and neglected children housed within Russia's vast orphanage system. Ten years ago, similar images appeared of wretched Romanian babies and children in appallingly squalid orphanages. The West was quick to respond with generous assistance to those institutions. But as Romania's minimal economic social net evaporated, that aid encouraged families unable to care for their kids at home — particularly kids with mental and physical disabilities — to give them up. The result was a 37 percent increase in Romania's orphanage population in just 10 years.



Children that are deemed to be self-abusive or "too bothersome" are restrained.

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The Way to Save Russia's Orphans

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Today, humanitarians in the U.S. Congress are poised to make the same mistake in Russia by funneling millions of dollars to Soviet-era custodial institutions. There is a humane, effective and economical alternative that should be implemented immediately to head off a tragedy of immense proportion.

According to the Russian government, there are 500,000 children in institutions, and an additional 100,000 kids lose their families every year, living on the streets or the orphanages. The vast majority of these children are so-called "social orphans" -- children with living parents who are left at institutions because poor families cannot feed them. Many have mental or physical disabilities for which there are no social services at the community level.

Until recently there has been almost no alternative for parents to placing their children in a state institution, and there are strong pressures to do that. But the children's lives are a horror once they are institutionalized: With family ties severed, little or no education and minimal emotional involvement from even the most well-meaning but overworked caregivers, their disabilities worsen.

Many kids are left lying on the floor for hours on end.

The goal of Russian disability rights activists is for every child to live in a family, and for the orphanages to eventually close their doors forever. It should be the goal of foreign donors, as well.

The plight of "orphanage" kids in Russia is not all that different from that of American children with disabilities 30 years ago. We, too, had virtually no social services for families or education for the children. Parents of kids with disabilities were often advised to place them in institutions.

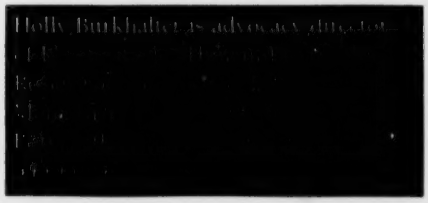
This 5-year old girl with Down syndrome has never been out of her bed.

But over the past few decades, activist parents and the burgeoning disability rights movement in the United States have transformed the lives of children and adults with disabilities. Although in some states pediatric nursing homes still exist, community social services and education are available now for youngsters with the most significant disabilities.

Change is likely to come in Russia the same way, if the United States and other donors do not discourage it by shoring up the Russian orphanage system. A handful of parents who have bucked social convention and economic disincentives and kept their children at home have joined to form the Down's Syndrome Association and other groups. They are lobbying the government for services, demanding schooling for their children and urging a reform of government policies so that families have incentives and support to keep kids at home. These brave efforts are starting to bear fruit. Authorities in the city of Samara have taken the initiative to remove children from orphanages and place them with families in the communities. Elsewhere, a handful of model foster care programs have begun, and there are several small, integrated schools in Moscow.

The goal of Russian disability rights activists is for every child to live in a family, and for the orphanages to eventually close their doors forever. It should be the goal of foreign donors, as well. It can be achieved -- at a cost savings -- by comprehensive and generous programs to subsidize families or foster families, mainstream kids into the educational system, and offer distressed parents at risk of abandoning their children cash payments, day care or rehabilitative services. Russian social workers need to be trained and assisted in monitoring the children once they leave the orphanages. Advocacy efforts by people with disabilities need to be supported.

The leading disability rights activist in the United States and Europe, Gunnar Dybwad, has concluded that "four decades of work to improve the living conditions of children with disabilities has taught us one major lesson: There is no such thing as a good institution." Children, especially those with mental or physical disabilities, invariably will suffer in Russian institutions, no matter how much foreign aid pours in. Their only hope for healthy and meaningful lives is for them to be taken out and placed in families that are supported by a network of local social services.



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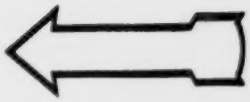
What Is Culturally Appropriate? Finding a Middle Way



BY ALEXANDRA ENDERS, RURAL INSTITUTE ON DISABILITIES, THE UNIVERSITY OF MONTANA

Introduction

Information is the medium for the communication of ideas. To improve equitable access to disability-related information and resources, the cultural context of information exchange needs to be considered. Cultural context is not just something to be aware of during international exchanges, it is a part of all human transactions.

A Recipe for Misunderstanding

Imagine this scenario: You have been asked for the best and most recent state-of-the-art technology. No one can pay for it, training to learn to effectively use it is out of reach, maintenance and repair will be a logistical nightmare, and it doesn't fit the intended environment. Does the person making the request live in an underdeveloped country, a major city in a developing country, an inner city in the industrialized U.S., or rural America?

> The outcome measures of our services and products should be based on the consumer's perception that something of value was received in the transaction. It doesn't make any difference that you see value in your intervention. If the individual or family you are working with finds it unacceptable or inappropriate to his/her life, it is.

The differences may not be as large as one would initially assume. There are striking similarities, much of it in the way information is presented and how issues of cross-cultural communication are approached. Assumptions about perceived value of available options must be clearly understood by all parties involved. You can provide information and access to resources that seem to appropriately meet the identified needs. However, if it is not presented in a format/context that the recipient values and trusts, it won't be an acceptable solution.

Striving Toward Valued Outcomes

We are in the business of increasing the impact and acceptability of effective strategies, products, research findings, technical assistance, and training opportunities in the lives of people with disabilities. The outcome measures of our services and products should be based on the consumer's perception that something of value was received in the transaction. It doesn't make any difference that you see value in your intervention. If the individual or family you are working with finds it unacceptable, worthless, or inappropriate to his/her life, it is.

Moving Away from a Black and White World

Not many years ago, a simpler worldview sufficed. Countries were either industrialized or underdeveloped, technology was either high-tech, state-of-the-art or appropriately low-tech, societies were either bountifully rich "haves" or poor, handout-seeking "have nots."

Things have changed. Old categories don't work. We need better ways to distribute available resources. With the socio-political changes underway in the world today it is naive to view the planet as composed of industrialized "haves" and underdeveloped "have nots." Many countries that were resource-poor 15 years ago are now considered at a mid-level, while the highly industrialized Eastern bloc countries are far from resource rich.

This is also reflected in rehabilitation/disability services, where we need models that present solutions in categories that fall in between the extremes of the high-tech rehabilitation centers and the World Health Organization's (WHO) community-based rehabilitation scheme. Neither of these "ends of the spectrum" approaches work very effectively in rural America. Professionals in specialized

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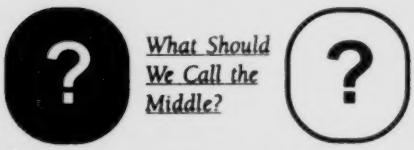
urban rehabilitation centers frequently counsel their patients from rural areas to remain in the city after rehabilitation because they are convinced that the necessary resources and supportive services will not be available if the person returns to their rural community. These cross-cultural biases (urban versus rural) and unquestioned assumptions are only compounded by ethnic and socio-economic differences. Diversity, the buzzword of the 90's, assumes an acceptance and value of different experiences — cultural, ethnic, socio-economic. There is little acknowledgement of diversity in rehabilitation today, in the U.S. or elsewhere.



A curious vacuum exists for effective strategies that are in the middle of the spectrum. Most of the words that fit already have other connotations. Intermediate and appropriate are distinctly tied to international development efforts. Appropriate technology is generally focused on the needs of people from rural areas in third world countries. When this approach is adopted by an industrialized country such as the United States, its target is usually the development and implementation of technologies appropriate for low-income communities, especially those in rural areas. Appropriate technology is grounded in cultural, political, and ecological frameworks; its proponents often share an almost evangelical zeal. Unfortunately, most professionals working at the sophisticated urban end of the spectrum have little appreciation for this approach. It also tends to be rejected by urbanites in major cities in underdeveloped and developing countries.

The U.S. National Center for Appropriate Technology (NCAT) stated that "The main goal of appropriate technology is to enhance the self-reliance of people at a local level." If we substituted the word "assistive" for "appropriate," we would have a useful mission statement for many individuals working in our field. Appropriate assistive technology doesn't have to mean cardboard seats and tire tread sandals. We need a way of using the concepts implicit in appropriate technology, and presenting them in a format that even the "high techies" can find acceptable and valuable.

A Closer Look From a Distance

International experience provides the outsider with a clearer view of his/her own culture, and the hidden assumptions that often lead to misunderstanding and miscommunication. It can also point to directions for developing new strategies.

Working in Armenia when it was still part of the Soviet Union made me more aware of the need for a "middle way" to approaching cross-cultural communication related to services for people with disabilities. My training and experience have enabled me to transcend the high tech/low tech gap. I've always been involved at both ends of the spectrum - the high tech environment of Stanford and the Electronic Industries Foundation, and the low tech world of DIY (do it yourself), scrounging for low cost solutions, and supporting projects in third world countries.

Uncovering Hidden Assumptions

More than one of the patients on the spinal cord injury rehabilitation unit in Armenia could have benefited from independent mobility while their pressure sores were healing. There were few gurneys available, and none could be spared to be fitted with drive wheels. David Werner's manual, Disabled Village Children, has a clever adaptation for turning a wheelchair into a self-propelled trolley. The orthotist was able to build the adaptation, and attach it to one of the heavy, fixed-armrest wheelchairs. The first patient was shown the pictures of how the device could be used (you essentially drive the wheelchair backwards). Compliantly he agreed to try it, but then refused to leave his room in it. After repeated discussions (all through an interpreter), it was finally clear that he felt he had been given a peasant device, and though he liked the freedom, he was embarrassed by the image he felt it portrayed. He stated that though he came from a mountain village, he was not a peasant. He refused to use the mobility device on the unit. Several weeks later, I found a project plan for an almost identical device in the appendices to Ford and Duckworth's Physical Management for the Quadriplegic Patient. The book had been circulating on the unit, the pictures in the chapter on sexuality being the major attraction. When the pictures of the similarly adapted wheelchair from the specialized rehabilitation book were shown to another patient, he was eager to try it. The original device was adjusted to fit. When presented with the adapted chair, he refused, stating it was the peasant device that we'd used with the other individual. I remain convinced that if I had presented the device to the initial patient as originating from the sophisticated Ford and Duckworth text, and not with pictures of barefoot peasants, that the acceptance would have been completely different.

Coming from a subset of American culture that will accept just about anything that works, it was amazing to me to see a useful device rejected because of the image it conveyed. The more I observed, the more I could understand why some things were accepted, while others were rejected out of hand. Much of the causality can be traced to the way the information,

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service, treatment, or product was presented.

This was not peculiar to Armenian mores. I worked as part of a multinational team with members from 15 countries. When I tried to introduce material from the World Health Organization's community-based rehabilitation (CBR) manuals, I found no support. Others, including the team leader from England and head nurse from Australia, felt these manuals inappropriate. After all, "we weren't in Africa." Having learned my lesson about using pictures, I assured them we would not use the pictures. The information in the manuals was directly applicable, but most of my colleagues could not get beyond the presentation style and format.

I returned to the U.S. convinced that we needed to develop better communication vehicles, that we were losing valuable information because we do not see the broader market possibilities, and instead only package data for a particular audience.

Collaborating on a Middle Way

Today, I see a broader audience than the two primary ones described. There has to be a middle way. Consider all the people who need the same basic content in the information developed for resource poor societies. A large number of these individuals are not and do not consider themselves peasants. The list includes the entirety of the former Soviet Union, the old former Eastern bloc countries and major cities in developing countries.

For example, much of the rural U.S. could be considered in this category. People in many rural areas experience anomalies in resource availability. They may have all kinds of high-tech machines available to them during inpatient treatment (continuous passive motion, electrical stimulators, biofeedback devices). But if they need ongoing assistive technologies, they are probably going to be left to their own devices. Most Americans probably would not balk at building something that came from a book intended for third world citizens. But for most people this material would be difficult to locate.

Characteristics of a Middle Way

Middle Way projects and communication methods incorporate:

- ❖ realistic economic and cultural context
- ❖ accurate understanding of cultural self-perception (i.e. the way people see themselves and want their neighbors in the world to see them)
- ❖ flexibility and the ability to see beyond the boundaries of one's own cultural interpretations
- ❖ mechanisms for mutual two-way exchanges
- ❖ emphasis on the value of contributions by all participants, including explicit identification of what persons unfamiliar with the native culture will learn and receive in exchange for what they bring to the project
- ❖ full participation and equitable sharing among all participants, not a charitable giving to needy folks
- ❖ sustainability and self-sufficiency

And sometimes it takes a little imagination to translate it. For example, a book from India has construction ideas for a low cart useful inside village huts, where most people cook and eat close to the ground. The same idea appears useful for a Native American dwelling which has high doorway thresholds which cannot be ramped due to the culture's spiritual belief system. The Indian trolley has a set of wheels that allow the driver to tip back and forth over a threshold. It would be valuable to take the Indian material and redraw it so it is more graphically acceptable to Native American applications.

Acknowledgements

I would like to thank Ralf Hotchkiss and Greg Dixon for the wisdom they have shared with me on these issues.

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1999 TASH Annual Conference
Special Event

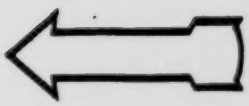
Join Lawrence Gorski, Director of the Chicago Mayor's Office for People with Disabilities

FRIDAY, DECEMBER 10
8:00-10:15 am

Mr. Gorski will lead a discussion of the voting rights, political voice and electoral opportunities for people with disabilities during the presentation "Awakening the 'Sleeping Giant' in the New Millenium.".

This session is part of the Governmental Affairs Strand.

Que Es lo Culturalmente Apropriado?
Buscando el Termino Medio



POR ALEXANDRA ENDERS, RURAL INSTITUTE ON DISABILITIES, UNIVERSIDAD DE MONTANA, EE.UU

Introducción

La información es el medio para la comunicación de ideas. A fin de mejorar el acceso equitativo a la información y recursos relacionados con las discapacidades se necesita primero considerar el contexto cultural del intercambio de información. El contexto cultural no es simplemente algo de lo que se debe de estar consciente durante los intercambios internacionales, sino que es parte de todas las actividades del ser humano.

Una receta para los malentendidos

Imaginese la siguiente situacion: Usted ha hecho un pedido de la mejor y mas reciente tecnologia del momento. Nadie la puede costear, la capacitación para usarla eficientemente esta fuera de alcance, el mantenimiento y reparación sera una pesadilla logistica y no se ajusta al ambiente para la que se le ha considerado. ¿Dónde vive su usuario, en un pais subdesarrollado, en una ciudad grande de un pais en desarrollo, en el interior de una ciudad industrializada de los EE.UU. o en una zona rural de ese pais?

Las diferencias puede que no sean tan grandes como se puedo imaginar al principio. Hay sorprendentes similitudes, mucha tiene que ver de que manera la información es presentada y como se enfrente a los temas de la comunicación intercultural. Las suposiciones sobre el valor percibido de opciones disponibles deben ser entendidas claramente por todos los participantes involucrados. Usted puede proporcionar información y acceso a recursos que parecen satisfacer las necesidades identificadas apropiadamente. Sin embargo si no es presentada en una forma/contexto que el recipiente valore y confie, no sera una solución aceptable.

En busca de resultados valiosos

Nosotros estamos en el negocio de incrementar el impacto y aceptación de estrategias efectivas, productos, resultados de investigaciones, asistencia técnica, y oportunidades de capacitacion en las vidas de las personas con discapacidades. El resultado de nuestros servicios y productos debe de basarse en las percepciones que los consumidores tienen de que algo de valor fue recibido en la transacción. No representa ninguna diferencia que usted vea el valor de su intervención, ya que si el individuo o familia con los que trabaja lo encuentran inaceptable, sin valor o inapropiado para su estilo de vida.

Saliéndose de un mundo en blanco y negro

No hace muchos años que bastaba tener una visión del mundo mas simple. Los paises o eran industrializados o subdesarrollados, la tecnologia era la mas avanzada o la mas obsoleta, las sociedades eran inmensamente ricas o pordioseramente pobres.
Las cosas han cambiado, las categorías viejas ya no sirven. Necesitamos mejores formas de distribuir los recursos disponibles. Con los cambios socio politicos a los que se enfrenta el mundo en la actualidad, es ingenuo pensar que el planeta sigue estando compuesto por industrializados que tienen y subdesarrollados que no. Ahora se considera de nivel medio a muchos paises que eran pobres en recursos hace 15 años, mientras que los altamente industrializados del bloque oriental están lejos de ser ricos en recursos.
Esto se refleja en los servicios de rehabilitación y discapacidad, donde necesitamos modelos que presenten soluciones en categorías que caen entre los extremos de los centros de rehabilitación de alta tecnologia y los esquemas de la rehabilitación en que se basa la comunidad de la Organizacion Mundial de la Salud. Ninguna de estas metodologias de "extremos del espectro" funcionan eficientemente en la zona rural de los EE.UU. Los profesionales de los centros urbanos especializados frecuentemente aconsejan a sus pacientes rurales que se queden en las ciudades

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Que Es Lo Culturalmente Apropiado? Buscando el Termino Medio

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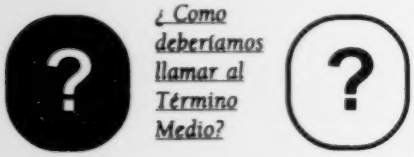
despues de ir a rehabilitacion, porque estan convencidos que no encontraran ni recursos ni servicios de apoyo cuando regresen a sus comunidades rurales. Estos prejuicios que sobrepasan las barreras culturales (urbano-rurales) e hipotesis que quedan sin cuestionamiento están compuestas de diferencias étnicas y socioculturales. Diversidad, término de moda en la década de los 90, asume la aceptación y valor de las diferentes experiencias culturales, étnicas y socioeconómicas. Hoy día hay un poco de reconocimiento de diversidad en la rehabilitación, tanto en los EE.UU. como en otros lugares.



Existe un curioso vacío de estrategias eficaces que están en medio del espectro. La mayoría de las palabras adoptadas ya tienen otro tipo de connotaciones. Ya que "intermedio" y "apropiado" están indudablemente ligadas a los esfuerzos de desarrollo internacional. La tecnología apropiada generalmente se relaciona con las necesidades de la población rural de los países del Tercer Mundo y cuando éste concepto es adoptado por un país industrializado como los Estados Unidos, generalmente su objetivo es el desarrollo e implementación de tecnologías apropiadas para comunidades de bajos ingresos, especialmente aquellas que están en áreas rurales. La tecnología apropiada se basa en esquemas culturales, políticos y ecológicos y sus autores generalmente comparten un celo casi evangélico. La mayoría de los profesionales que trabajan en el medio urbano sofisticado, desafortunadamente poco aprecian esta metodología que también tiende a sufrir rechazos de la población urbana de las ciudades grandes de los países subdesarrollados y desarrollados.

El Centro Nacional para la Tecnología Apropiada de los EE.UU. (U.S. National Centre for Appropriate Technology) ha declarado que "La meta principal de la tecnología apropiada es la de mejorar la auto suficiencia de la población a nivel local". Si nosotros sustituimos la palabra "asistida" por la palabra "apropiada", podríamos tener una declaración de principios para muchos individuos que trabajan en nuestro campo. La tecnología de asistencia apropiada no necesariamente significa asientos de cartón y sandalias de suela de neumático. Necesitamos de alguna manera usar conceptos que están implícitos en la tecnología apropiada y presentarlos en un formato que aún los partidarios de la "alta tecnología" pueden aceptar y valorar.

Una mirada cercana desde lo lejos

La experiencia internacional le ofrece a aquellos que vengan de otros lugares, una mas clara visión de su propia cultura y de los prejuicios escondidos que generalmente llevan a malentendidos y falta de comunicación apropiada. También pueden llevar al desarrollo de nuevas estrategias.

El trabajar en Armenia cuando todavía era parte de la Unión Soviética me hizo mas consciente de la necesidad de encontrar una "término medio" para enfrentarme a la comunicación intercultural relacionada con los servicios de la población de personas con discapacidades. Mi capacitación y experiencia me ha permitido trascender el vacío entre la alta y la baja tecnología. Siempre he participado en los dos extremos del espectro: el ambiente de alta tecnología de Stanford y de la Electronic Industries Foundation, y el del mundo de baja tecnología llamada "haslo tu mismo", que busca soluciones de bajo costo y apoya proyectos en países del Tercer Mundo.

Revelando suposiciones escondidas

En Armenia, por lo menos uno de los pacientes de la unidad de rehabilitación de lesiones de columna se podría haber beneficiado de tener movilidad independiente mientras las heridas causadas por la posición en que se encuentra todo el tiempo mejoraban. Se disponía de pocas camillas y a ninguna de ellas se les podía poner ruedas direccionales. El manual de David Warner, "Disabled Village Children," tiene formas ocurrentes de como adaptar una silla de ruedas en una camilla donde la persona se pueda impulsar por sí misma. El ortista pudo construir esta adaptación y añadirla a una de las sillas de rueda pesadas con descansa brazos fijo.

Al primer paciente se le mostró fotos de como se podría usar el "aparato" , (tu simplemente maneja la camilla adaptada en reversa). Se mostró interesado a probar el "aparato", pero se negó a salir de su cuarto el. Después de varias discusiones a través de un intérprete quedó en claro que creía que le habían dado un artefacto para campesinos, y aunque le gustaba la idea de independencia, le daba verguenza la imagen que daba. Dijo que aunque venía de un pueblo en la montaña, él no era un campesino y se negó a usar el "aparato" móvil en la Unidad.

Semanas después hallé un proyecto para un aparato casi idéntico en las páginas del libro titulado "Physical Management for the Quadriplegic Patient" de Ford y Duckworth. El libro había circulado en la Unidad, las fotos en el capítulo sobre sexualidad eran las de mayor atracción. Cuando se le mostró las imágenes de una silla adaptada en forma parecida a otro paciente que la necesitaba, se mostró ansioso de probarla. Se ajustó el diseño original para que el paciente pudiera usarla. Cuando se le mostró la silla adaptada, la rechazó diciendo que era el aparato para campesinos que uso el otro

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paciente. Quede convencida que si se le hubiera presentado el aparato al primer paciente como si fuera el diseño original y no con fotos de campesinos descalzos, la aceptación podría haber sido diferente. Viniendo de un subconjunto de la cultura norteamericana que acepta cualquier cosa que funcione, me asombró ver el rechazo de un dispositivo por la imagen que proyecta. Al observar mas detenidamente, pude entender por qué algunas cosas eran aceptadas mientras que se rechazaba otras sin considerar su valor. Mucha de la casualidad puede ser identificada de como se presentó la información, el servicio, el tratamiento o el producto. Esto no es peculiar en las costumbres de Armenia. Trabaje como parte de un equipo multinacional con miembros de 15 paises y cuando traté de presentar materiales de los manuales de las rehabilitación basada en la comunidad (RBC) no hubo apoyo. Otros, como el jefe del equipo británico y la enfermera representante de Australia creyeron que los manuales eran inapropiados. A fin de cuentas, "no estabamos en África," dijeron. Aprendida mi lección sobre el uso de fotografías, les aseguré que no las usaría mas. La información de los manuales se podía aplicar directamente, pero la mayoría de mis colegas no pudieron ir mas allá del estilo y formato de la presentación.

Regresé a los EE.UU. convencida que necesitamos desarrollar mejores formas de comunicación y que estamos perdiendo información valiosa porque no podemos ver mas allá de las posibilidades del mercado, ya que sólo se prepara la información para un audiencia en particular.

Colaborando en un Término Medio

Hoy puedo ver que hay una audiencia mayor que las dos antes descritas. Debe de haber un Termino Medio. Considerar toda la gente que necesita el mismo contenido básico de información desarrollada para sociedades pobres. Una gran parte de estos individuos no son ni se consideran campesinos. La lista incluye la totalidad de la ex Unión Soviética, el viejo ex bloque de paises orientales, y la mayoría de las ciudades de los paises en desarrollo.

Por ejemplo, gran parte del área rural de los Estados Unidos se puede considerar en esta categoría. La gente de muchas áreas rurales experimenta anomalías en el acceso a recursos. Muchos de ellos puede que dispongan de todo tipo de maquinas de alta tecnología en el tratamiento de pacientes: como las de movimiento pasivo continuo, estimuladores eléctricos y de bioalimentación. Pero si necesitan continuamente de tecnologías asistidas, probablemente deberán terminar usando sus instrumentos propios. Muchos de los norteamericanos probablemente no dudarían en construir algo que aparece en un libro para ciudadanos del Tercer mundo. Pero para la mayoría de ellos sería difícil conseguir los materiales y a veces se necesitara algo de imaginación para traducirlos. Por ejemplo, en un libro de la India contiene ideas de como construir un carruaje de baja altura útil solamente dentro de las chozas de una villa, donde la mayoría de la gente cocina y come casi a nivel del suelo. La misma idea parece ser útil en las casas de los indígenas norteamericanos que tienen umbrales altos a los cuales no se les puede poner rampas dadas sus creencias religiosas. La silla automotora india tiene ruedas que le permiten inclinarse hacia atrás y adelante para saltar el umbral. Sería valioso tomar el material indio y rediseñarlo para que fuera mas gráficamente aceptable a las aplicaciones de los indígenas norteamericanos.

Características del Término Medio

Los proyectos de Término Medio y los métodos de comunicación incorporan:

- contextos culturales y económicos realistas
- comprensión veraz de las auto percepciones culturales (por ejemplo, la forma en que la gente se ve a sí misma y cómo desean que sus vecinos del mundo los vean
- flexibilidad y capacidad de ver mas allá de los límites de sus interpretaciones culturales
- mecanismos de intercambio mutuo de ambos lados
- énfasis sobre el valor de las contribuciones de todos los participantes, incluyendo la identificación explícita de lo que los extraños recibirán y aprenderán en intercambio de lo que ellos aportarán al proyecto
- participación total y distribución equitativa entre los participantes, no dar caridad a las gentes necesitadas
- autosuficiencia y manutención

Reconocimientos

Deseo dar las gracias a Ralf Hotchkiss y a Greg Dixon por la sabiduría que han compartido conmigo en estos temas.

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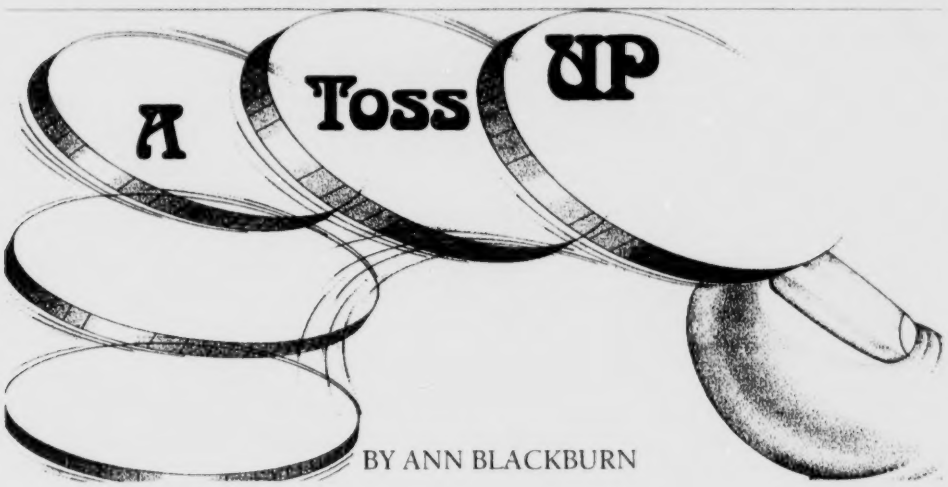
We gratefully acknowledge the invaluable assistance of TASH Executive Board member Jorge Pineda in providing the Spanish-language translation of this article.



BY ANN BLACKBURN

Coming back to England after spending six weeks in Portland, Oregon, was a real eye-opener. It was also rather depressing because returning to the U.S. reminded me of how independent I could be. Since I moved back to England from Portland three years ago, despite my efforts, I have found it almost impossible to participate in mainstream society. I feel that I am missing out on life.

Accessibility in the U.K.

Like any other 22-year-old woman, I like to go out and have a good time. For two reasons it is very difficult to travel about in London. First, the lack of accessible public transportation means using taxis, which can be very expensive, especially because wheelchair accessible taxis tend to be a lot costlier than non-accessible taxis. Second, chances are that even if I do manage to arrive at the building I am going to, it will not be accessible. Needless to say, I do not get out as much as I need to or want to.

I remember the time that I went to the theater in London with a couple of friends. We took the subway to Kings Cross station and hired a cab to get to the theater. The cab driver did not know how to use the ramp on his own cab and my friend had to show him. When we got to the theater, the accessible entrance for people using wheelchairs was a make-shift ramp around the side entrance. Our seats were down a flight of stairs where they put two planks as ramps. It took three grown men to get me back up. When I booked the tickets, they told me that the theater was accessible.

> *"My summer in Portland reminded me of what is possible. I was able to go where and when I wanted without [a lot of advance booking or] long-term planning...." What 22 year-old would want to be bound by inaccessibility to transportation or inability to access buildings and other structures? For that matter, why should anyone have to live like this?*

I live alone, so going out and meeting people is important to me. When I go out, I need to book transportation in advance and that sometimes limits me. If I forget to book or it is a last minute decision, I cannot go. A lot of the time it is such a hassle to book transportation and make sure the destination is accessible, that I feel it is not worth it. I feel trapped and so lonely because I find it so difficult to get out. What 22 year-old lives like this?

My summer in Portland reminded me of what is possible. I was able to go where and when I wanted without long-term planning because all buses and light rail trains are equipped to carry people that use wheelchairs. It was convenient not to have to worry about whether or not I could get into buildings; most are accessible.

England has made some improvements, and is a lot easier to travel around than it was five or ten years ago. All buildings are supposed to be wheelchair accessible by 2004. I really don't see how that can be accomplished in large cities like London that are old and so densely populated. After my visit to Portland and having the feeling of independence due to greater access to mobility, upon my return to England I feel that I have made a major step backwards in this part of life.

Social Benefits

One thing I will say about being here is that the United Kingdom does a good job of assisting people with disabilities through the benefits system. Those who get everything they are entitled to are able to live quite comfortably.

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A Toss Up

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A drawback, however, is that benefits in England are so good that the indirect result is that it encourages people to stay at home and not fulfill their potential. For many people that receive benefits it is actually not worth working because as soon as you secure a job, doors to money and services start to close. For example, after you get a job, social service starts to charge for home care.

In the United Kingdom the benefit system is generous to the point where most people do not need to have full time jobs to survive. By contrast, in the United States the benefit system is lacking in many ways and as a consequence, people need to find jobs. On the one hand, this may force people with disabilities into mainstream society and may help to close the social gap between those who have disabilities and those who do not. While this may be all very well for people who can work, if work is not an option the United States is not the place to be.

Education

Years ago children with disabilities were sent to special schools, if they went to school at all. This was equally true in both the United Kingdom and the United States. Having lived in both countries, I have experienced both segregated and inclusive education.

Before my family moved to the United States, I went to a school for children with disabilities. Although I was not being challenged, I was happy there because I did not know what I was missing. This sets a pattern for segregation in later life. When school finally ends, the person with a disability has been in a protected environment and, therefore, has missed out on gaining those important social skills that will be needed. The first time I returned to England, three years ago, I went to visit an old childhood friend. She had remained at the segregated school I had attended until she was old enough to leave. She then went on to a college for people with disabilities. Sadly, we no longer had anything in common. I found her to be lacking in the most basic social skills.

When it comes to providing services and facilities for people with disabilities both countries have their advantages and disadvantages. In a perfect world, I would like to see a system where the best features of both countries are combined.

Here in England people with disabilities are usually congregated together. It is not surprising, then, that the general population is not used to being around people with disabilities. Children without disabilities are not used to being around those of us with disabilities, so when they get out in the world and meet us they do not know how to relate to us.

The United States, or at least Oregon, seems to have the right idea on this issue. Inclusive education is the way to go. In Oregon, if the parents of a child with a disability want their child in an inclusive classroom, the school basically has to comply. When I moved to Portland at the age of ten, I attended my neighborhood elementary school. The school provided a personal assistant in the classroom to help me with note-taking and writing. I had a lot of catching up to do because when I entered mainstream education I was at least two years behind my peers. I caught up quite quickly and graduated with honors. I am so grateful that I was able to fulfill my educational potential. Now I am looking at a career in desktop publishing. I believe that being in an inclusive educational placement is responsible for building my self-esteem and allowing me to become who I am today.

It is true what they say: "you don't know what you are missing until you lose it." Since I was essentially raised in an inclusive environment, I don't feel that I fit into the so-called "disabled" scene.

In the past several years I have tried in countless ways to participate in mainstream society and improve my life. Some of my attempts have worked, but mostly I have come across other barriers. It seems as if I take three steps forward and two backward.

Unfortunately, I feel that I am missing out on a time of life when I should be out discovering who I am and who I want to be. All I want is to be able to live my life in a way that suits my personality. Eventually, I will probably move back to Portland where I feel less trapped.

When it comes to providing services and facilities for people with disabilities both countries have their advantages and disadvantages. In a perfect world, I would like to see a system where the best features of both countries are combined. In truth I do not know where the answer lies.

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Living Person-Centered Planning in the Village of Kumbayah

BY SHINA ASANTE AHAD AND BAHIYA CABRAL ASANTE

Eight years ago, after almost a decade of intense community organizing around issues as diverse as keeping a neighborhood fire station open and developing youth leadership, members of New African Voices Alliance (NAVA) evaluated our work and its impact. Our vision was a society where each individual could thrive, where human relationships were based on love and respect, and where both political and economic democracy were the order of the day. However, in looking back over years of work, we recognized that we had lost many people along the way.

The real life needs of these individuals took them away from working to improve their block, neighborhood, city, and society. Many times, economic needs did not allow the time and energy for community organizing. People also had pressing family needs, including the desire to actually spend time with their loved ones every once in awhile, as well as the overwhelming needs of children growing up in a world where temptations are many. In the words of the co-founder of NAVA, Shafik Asante, "People are too busy struggling for their economic survival to think about their human liberation."

In a village, children have the combined care of many people, extended "family" members to whom they can go. Person-centered planning works the same way in the village.

Out of this evaluation a new concept was born. Actually, it's probably not new as there is "nothing new under the sun." Yet, it is definitely something we've gotten away from in the U.S. -- the concept of community building, or what we in the Village of Kumbayah call *villaging*. As African people, we once believed in the village concept -- raising our children in an atmosphere of shared love, support, and discipline. In a village, children have the combined care of many people, extended "family" members to whom they can go.

Person-centered planning works the same way in the village. The person in need of support receives it from an entire group of people who value that person and have an emotional investment in his or her growth and success. When it has been determined that someone needs extra support, it is customary for him/her, his/her parent/guardian or other key person(s) to present the situation to the gathered villagers. Once the situation has been laid out, a committee may be chosen by the person or people may volunteer. That committee will look into the various options that are available for that particular situation. Then they will ask the person who is being supported what goals are expected. In this process, we use person-centered planning tools. When we have worked with a villager in resolving a problem or plotting a course to a goal, we then have periodic check-ins to make sure that things are moving according to plan and to identify what modifications or additional supports, if any, are needed.

Our most complex experience with person-centered planning occurred when Shafik Asante was hospitalized in 1997. We often refer to Shafik as the heart of the Village of Kumbayah. He battled cancer for 20 years, but still was able to model for us what villaging was all about. In 1994, Shafik did a MAP (an information gathering system that creates a positive portrait of a person by working with his/her friends, family and colleagues) that was invaluable to us in

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Living Person-Centered Planning in the Village of Kumbayah

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determining the kind of care he wanted to receive. We knew that it was necessary to provide round-the-clock support, so we came together and drew up a plan. The plan insured that he was never at the hospital alone, that all hospital care that he received was monitored, and that he was always treated with dignity and respect. This was especially critical towards the end of his hospitalization, as he was not able to insist upon those things for himself.

For example, Shafik always required that doctors treat him as a whole person -- speak directly to him, ask him questions, let him know what they were doing. We insisted that these practices continue when he was unable to speak. We made sure that his favorite music was played, that his symbols that he valued were placed around the room; that, in fact, the environment in his room was as close to home as possible. The requirements of his care were shared by all villagers. At the same time this provided needed support to his family and to everyone in the village during this especially painful experience. It was necessary for us to pull together, and we did.

Shafik passed away on September 5, 1997. Supporting him was the first major test of person-centered planning in our village. We had utilized it before but never in a situation that required so much of all of us or where the person was not able to directly communicate his wishes. We struggled to insure that Shafik's needs, as he saw them, were put first, and for us that is the heart of person-centered planning.

Reprinted with permission from Shina Asante Ahad and Bahiya Cabral Asante, IMPACT, Vol. 11, No. 2, Fall '98, published by the Institute on Community Integration (UAP), University of Minnesota.

In Commemoration of John F. Kennedy Jr. -

Lost Champion of Direct Support Professionals and People with Disabilities

The loss of John F. Kennedy, Jr. leaves us saddened and has many of us pondering his legacy. Of the many things for which he will be remembered it is hoped that his contribution to those who provide direct support to people with disabilities will be among them.

Aware of how underpaid, under-recognized and undervalued frontline workers are and how this impacts the people who need support, John F. Kennedy, Jr. responded in 1989 by founding Reaching Up, Inc., a non-profit organization devoted to providing higher education and career opportunities for Direct Support Professionals (DSPs). Since that time, Reaching Up, Inc. has provided mentoring, higher education, opportunities to join professional associations and attend national conferences, and other support for Direct Support Professionals who are committed to their work. Through Reaching Up, Inc., John F. Kennedy, Jr. also helped to found the National Alliance for Direct Support Professionals.

Mr. Kennedy recognized the need for both Direct Support Professionals and people with disabilities to share dialogue around important issues on an ongoing basis. It was for that reason Reaching Up, Inc. supported the publication of *Frontline Initiative*. Writing in the premier issue of the *Frontline Initiative*, Kennedy said, "We need more forums like these, outside of the service environment, where workers and people with disabilities can talk directly to each other to discuss their common interests as well as differences. As allies with a shared agenda, they can help each other achieve their goals."

John F. Kennedy, Jr. saw this publication as a way to foster communication and networking among the millions of Direct Support Professionals and Self-Advocates around the country. Reaching Up, Inc. funded several initial printings of the newsletter, and the organization continues to support this publication through editorial participation and writing assistance.
While serving on the President's Committee on Mental Retardation, Mr. Kennedy co-sponsored many initiatives of the President's Committee that promote better lives for both DSPs and people receiving supports. Among them are the Next Generation Leadership Symposium, an annual conference for developing leadership among younger DSPs, and several publications, including: *Opportunities for Excellence - Supporting the Frontline Workforce; Voices of the Next Generation*; and *With a Little Help from My Friends.*

As an expression of gratitude for the many contributions John F. Kennedy, Jr. made to improve the status and well-being of direct support workers, *Frontline Initiative* will feature a special tribute to him and his accomplishments in this arena. The issue will be a commemoration by those who knew him and worked with him on these issues, including DSPs whose lives he influenced through his foundation and personal attention to their issues.

- Bill Ebenstein, CUNY

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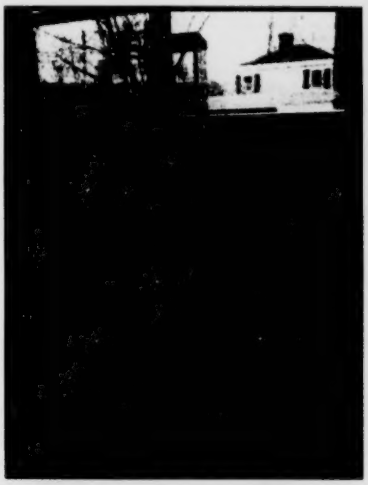
I'm not in Special Education Anymore: My Name is Peter

BY PETER HUNTON WITH MARY BETH DOYLE

I am a tall, handsome, single guy. I am 22 years old. I am a college student and I am NOT a special education student anymore. I like playing basketball, exercising, and hanging out in downtown Burlington (Vermont). I like being with my friends. I like jazz and rock-and-roll music. I like school, too, because now I am taking very interesting classes. I especially love my History of the '60s class. I've gotten more out of that class than out of any other class that I've ever taken. I never liked any other class before. I like that class because the teacher has a sense of humor and teaches a lot about women's issues, the Vietnam War, and the Civil Rights Movement. It's really powerful stuff. The class is outgoing and busy.

I don't like boring teachers. Boring teachers teach slowly and don't have a sense of humor. I had a lot of boring teachers in high school because I was in special ed. In high school, if you're in special education classes, they make you do stupid things like brushing your teeth in school. That isn't good because that stuff you do in kindergarten. I don't think the other kids in special education liked it either. They also give you stupid kindergarten contracts when you're in special ed in high school. It is a good thing that I had a good case manager because she said I didn't have to do stuff that I thought was baby stuff.

I was in high school for 6 years. That's a long time to be at a place that you don't like. Another reason I didn't like high school much at all was because the kids were mean. They would pick on the kids in special ed and call us "retards." I think they didn't care because they were with their friends and they weren't friends with kids in special ed. Some of the kids in special ed would pick on the kids in special ed too. I don't quite get why, but I think it was because they were jealous because they didn't want to be picked on, either.



That's me on the right. The picture is from a building project that I helped with at Trinity College of Vermont. The other person in the picture is Dr. Garet Allen-Malley. She is in charge of the Education Department.

In high school my teacher always had someone on my back. The person was like a tour guide. There was always a teacher or aide hanging on my back like I was a baby. Now I don't have people hanging out on my back because I'm not a special education kid anymore.

I couldn't participate in sports or anything in high school. I wasn't in any clubs because I didn't have any friends.

I hated being in special education because when people talked to me, they talked to me like I was a baby. They talked very slow and very loud as if I were deaf. I wish they would have talked to me like they do to other adults. They talk to them like adults. I hated being in special education because I didn't have any friends. Now I dream about having friends. I'm not special ed, so I can make friends now. People take me seriously now. Now I'm not special ed and I have a friend named Chuck. Chuck goes to college, too. We exercise and play basketball.

I'm not special ed anymore. My name is Peter. I'm a college student. I like college because it is open and people like to talk to you. The other students don't care if you were special ed or not when you were in high school. I'm a lot happier now because I have friends. Mostly the other college kids don't treat me like a baby. But sometimes, the other adults do treat me like a ten year old kid. Maybe it is because the adults never grew up with special education kids. Those adults grew up in the '60s and then the special ed kids were put away.

I learn a lot more stuff now, too. I get to learn stuff I never learned before. The important things that I learned this year are how to speak more clearly and to share my ideas. I've also learned how to joke around with people. I really like college. Now people call me by my name. . . they don't call me names. My name is Peter and I am not a special ed kid anymore.

1999 TASH Annual Conference

Special Event

"Nothing About Us Without Us"

Join us for a presentation by James Charlton, author of the book, *Nothing About Us Without Us: Disability Oppression and Empowerment*, a book The Nation called:

"the most expansive discussion of the disability rights movement in a political, economic and global context" yet written.

Friday, December 10
2:45 - 3:45 PM

How Independent Living Has Changed My Life: Some Stories from Latin America, Spain & Cape Verde

BY ROSANGELA BERMAN-BIELER

Rosangela Berman-Bieler's IDEAS Fellowship utilized a survey to elicit descriptions and opinions on the status of independent living efforts in Latin America and countries in Europe and Africa where the main language is Spanish or Portuguese. Following are some personal stories by some of the respondents and an analysis by Ms. Berman-Bieler of the overall implications.

Latin America

Argentina

●Virginia: "My life improved a lot because there is a big difference between living in an institution and sharing a house with two girlfriends. I used to work in a protected workshop and now, working for the Fundacion Prever, I work in the laundry department where I can relate to the public.

I like to do the housekeeping, to go shopping, care for my personal things and to keep every thing in order. I share everything with my girlfriends. I like to go places and I can manage myself perfectly well, even with my physical disabilities. I enjoy the tranquility of my home and my free time. I now receive a salary, which allows me some personal pleasures after paying my bills."

"I changed very much my point of view in relation to disability with the comprehension of what 'independent living' means: not to look at disability with the perception of sickness and impotence anymore, but to perceive life, potential and capacity to create models of pleasure and mobility."
Lilia (Brazil)

●Victoria: "To date in our country, Independent Living and social integration are realities for only a few individuals with a healthy financial situation. We still face racial, gender and economic discrimination. And a person with a disability suffers double discrimination."

Brazil

●Lilia: "As a psychologist, I have always been professionally connected to rehabilitation and as a person with a disability, I have always been connected to the disability rights movement. To participate in the group that founded the Center for Independent Living of Rio de Janeiro was a realization of an old dream that I had with other associates. I changed my point of view in relation to disability with the comprehension of what 'independent living' means: not to look at disability with the perception of sickness and impotence anymore, but to perceive life, potential and capacity to create models of pleasure and mobility."

●Alexandre: "I am a quadriplegic and the independent living philosophy brought me a new way of thinking and acting with relation to work, leisure, culture and quality of life. Through this new philosophy, I had to restart my professional and personal activities. Now I show other people in my region the importance of managing your own life, to participate effectively in a society where everybody has the same rights and responsibilities...".

Honduras

●Yolanda: "The Independent Living philosophy in Honduras has been in existence since the 1980's. Before that, one would not see people with disabilities in public areas, in school or recreational areas. Since then, the change in society has been very significant. Nowadays, people with disabilities are more integrated and can be seen everywhere. Although we realize that the architectural and social barriers are still extensive, they are not insurmountable."

Mexico

●Evelia: "When I became paralyzed I told myself: 'everything has changed and now I belong to another sector where I have to help myself.' I took the initiative to organize a group of people with all kinds of disabilities and, even in my own poverty and ignorance, I tried to figure out a way to support the most disadvantaged members of the group because they can not make themselves heard.

From the beginning, integration into the community and the family was very difficult for me because I believed that I was not useful to anybody. But when I started working again and founded the group, these feelings disappeared. Now, those who know me or know about my activities call me "Polvorita" (gunpowder) or "Capitana" (the captain) because I like punctuality and accomplishing plans; I do not tolerate irresponsibility or indifference. When an individual with a disability needs help, we will do everything in our power to respond. For me, people with disabilities always come first."

Panama

●Dominga: "In Panama there are no job sources for us. In our country we have very little assistance from the government, and we would like to know how people in the U.S. can help us. Our group, composed of 75 members, meets

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How Independent Living Has Changed My Life: Some Stories from Latin America, Spain & Cape Verde

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in a place lent to us by the community, but since we can not provide transportation only a few members are able to participate in the meetings."

> ***"The situation of people with disabilities in my country is very difficult because most people are illiterate, do not have any kind of training or profession and are beggars in the streets. Our association is trying to mobilize and to educate people with disabilities for a change of attitude".***
> ***Farida (Mozambique)***

Europe

Spain

●Eduardo: "We are a non-governmental organization and because official agencies provide minimal support to organizations such as ours, we took it upon ourselves to achieve financial autonomy. We combined the social with the business approach, applying entrepreneurial management criteria. For example, we own a residential building with 24 rooms where individuals with less significant disabilities assist those with more significant challenges.

Financial freedom is essential to the development of independent living. Today, the association is comprised of 170 employees, only 20 of whom do not have a disability. In these cases, the positions had to be filled by exceptionally good professionals, for example, lawyers and journalists. It's fine if a person with a disability qualifies for a position, but the most important requirement is that the person be a good professional, serving the ideals of social integration of people with disabilities.

In the 10 years of our existence we have mediated the employment of more than 1000 people with disabilities, providing them with social and psychological support, assisting the employers with information and consultation. This is a pioneering model of social intervention in Spain and the results are amazing. Today, 80% of our annual budget is sustained by our own programs."

Africa

Cape Verde

●David Antonio: "In 1976, I finished University, graduating in Agrarian Technical Engineering in Portugal. The Portuguese Government sent me for an internship in Cuba to conclude my thesis and receive my diploma. On the first day of the internship I was in a bus accident in the Cuban province of Guantanamo. I was left with paraplegia and at that time it seemed as if everything was finished for me. I returned to my country using a wheelchair and I was surprised to find that here I received from the government, my family and friends, all of the support I needed to create an independent life. I obtained my diploma and started to work. The government paid 50% of the cost of my automatic car to facilitate my mobility and transportation. I am married and have a beautiful family. I am a Seventh Day Adventist and run a church.

I feel I have realized and perfectly integrated into society. I consider my process of integration a model, and it proves that society has something to gain if it creates conditions for everybody to achieve an independent life."

Mozambique

●Farida: "Since I was a child my parents had the desire to enroll me in school. After high school, I studied to become a teacher and started to teach on the elementary level. In 1977, I entered the University to get my teaching degree. In 1995 I finished the Masters program. The situation of people with disabilities in my country is very difficult because most people are illiterate, they do not have any kind of training or profession and are beggars in the streets. Our association is trying to mobilize and to educate people with disabilities."

Final Considerations

The differences between the independent living movement in Latin or developing countries and in Anglo-Saxon or industrialized countries can be similarly compared to the cultural, social and economic aspects of human development in each country or region.

1. Paternalism

Family values, for example, are significantly stronger in the Latin culture than in other cultures. Autonomy is a strong characteristic of the Anglo-Saxon culture. These cultural differences are reflected in the disability field as well as in all other aspects of society. In the predominantly Catholic Latin America (we can include Portugal, Spain and the African countries surveyed), the entire culture is heavily centralized on the power of the Church and the family, and thus, in the State. The natural way to treat problems is through "paternalism": initially within the family, followed by the State and finally, from society in general.

Because of this type of relationship, it became easier for Latin countries to use campaigns such as "telethons" than to change the structure of society to integrate people with disabilities. Governmental benefits like free public transportation exist in theory, but are not made viable. Buses or subway systems are not accessible, and it is easier for people with disabilities to pay for palliative measures than to work for future definitive solutions.

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How Independent Living Has Changed My Life: Some Stories from Latin America, Spain & Cape Verde

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2. Personal Assistance

The research reveals that one area that reflects a large cultural difference in independent living is the area of Personal Assistance Service (PAS). Analyzing the responses about definitions of independent living, PAS was not mentioned as an aspiration of people with disabilities. In Latin America, this is not yet an issue under discussion, nor is it even brought up. If you take into consideration the importance of the family as the base of all social relations in the Latin culture, you understand the reason.

According to an article written by Kathy Martinez of World Institute on Disability entitled, *Cultural Adaptations of Independent Living Philosophy: Some Preliminary Observations*, in the IDEAS 2000 Portfolio'96, "in the U.S., PAS is based on the assumption that all adults with disabilities want to live outside their parents' homes. You have to ask yourself, 'Whose definition of independence this is?'" Ms. Martinez continues the discussion, considering that "in many cultures, independence means being able to contribute financially or otherwise to the family in a way that is respected by the community. In the U.S. PAS is assumed to be performed by paid strangers under the best of circumstances. In other cultures, family members may be the preferred providers," she concludes, expressing exactly the Latin culture's modality.

3. Terminology

The survey also revealed that the term "Independent Living" is not used by many organizations in Latin America and it does not reflect the Disability Rights Movement in which people with disabilities themselves advocate for the equalization of opportunities for the group.

But using the term "Independent Living" or not, the people with disabilities who are organized through the Disability Rights Movement have a precise understanding of what it means. In most cases, the term is misinterpreted by technicians or "specialists" from the rehabilitation and special education fields.

Many professionals insist on the use of terms that people with disabilities refuse to use, such as "normalization" or "integration." Members of the disability community prefer to use "right to difference" or "equalization of opportunities."

From the responses we can note clear conflicts among those concepts: the terms "normalization and integration" propose to "soften" the differences of people with disabilities and to adapt them to the status quo of society. The terms "right to difference and equalization of opportunities" intend to recognize and to equalize the differences, to adapt society to all members, with their vast range of peculiarities, including disabilities.

The first case is stimulated by distorted concepts and stereotyped images of people with disabilities going from "poor little-cripple" to "super-hero," typically the mentality of people who are not used to co-habiting community spaces with people with disabilities or simply envision them as "patients."

4. Providing Services

The main distinction between the Independent Living Movement in industrialized countries and the Spanish/Portuguese speaking countries researched seems to be that for the Latin countries, the provision of disability services is the base of the "new wave" of the Disability Rights Movement. The services now often include Independent Living Centers or programs.

Until the end of the 1980's, the main and only activity of organizations run by people with disabilities in the Latin countries was advocacy. They were mostly based on volunteer work, having few professionals involved as staff. They did not provide individual services of any kind for their peers, not even counseling or housing.

Recently, these organizations began to realize that their role should not stop there. In countries where rehabilitation reaches only 2-3% of people with disabilities and where the traditional models are not acceptable anymore, people with disabilities are stepping in to provide and to control certain disability services, such as in the new Centers for Independent Living of Brazil.

5. Empowering Individuals

It is important to point out that the concept of service provision by people with disabilities for people with disabilities is a relatively new development in Latin countries, appearing roughly in the late 1980's. Prior to this, the major focus of the disability rights movement was improvement of the status of the group as a whole -- through legislation, policy, and representation. This new development, more or less an Independent Living Movement, is characterized by services to empower people with disabilities.

6. Agents of Change

Research Fellow Kathy Lysack stated in her report entitled, *IDEAS 2000 Independent Living Survey: International Findings*, although the principles of self-determination and autonomy guide most disability organizations, there is pressure in low-income countries to provide disability services because of inadequate national rehabilitation systems and social services." This applies to Latin America today, where organizations of people with disabilities and parent organizations are changing their original dependency on the government to solve their problems and are taking the initiative as agents of change, providing the needed services themselves.

Continued on page 26

How Independent Living Has Changed My Life: Some Stories from Latin America, Spain & Cape Verde

Continued from page 25

7. Social Inclusion
The new approach is causing a major change in the traditional social structure of the region, as well as generating new concepts like "integrated education." The services are leaving the hands -- and control -- of the specialists and passing into the hands -- and control -- of the clients. They are starting to change from mere "patients" to active agents of their own social inclusion.

Many specialists and institutions began to complain, arguing they are losing their "market." Some are realizing that they must also follow the new trend and change their approach.

8. Survival Strategy
In reality, this is a political revolution, but different from those to which Latin American countries are accustomed. This time it is not from one dictatorship to another, but from the dictatorship of the traditional medical and institutional models to full citizenship and participation, with responsibility.

In a final analysis, there seems to be a global process of awareness, not just in the disability field, but a crying need of every person to fully exercise rights and responsibilities to make the world a better society for all. This could very well be a "survival strategy" for human beings at this end of the century.

9. Holistic Approach
As human beings, the issues related to people with disabilities have to be understood and treated in a holistic way, as part of all social, cultural, political and economic relations. The challenges of disability are only one issue to be considered in the context of all social roles of each individual. Equal opportunities, respect for individual differences and independent living are concepts that can be applied to most citizens in developing countries and, specifically, in Latin America.

10. Legacy
The application and improvement of these concepts can be the best legacy from people with disabilities to society as we enter the next millennium.

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Rosangela Berman-Bieler is President of the Inter-American Institute on Disability in Rockville, Maryland. Berman-Bieler is a Brazilian journalist, publisher and disability rights advocate. Founder of the Independent Living Movement in Brazil, she is also a founding member and former president of ONEDEF (the Brazilian Organization of Persons with Physical Disabilities) and CVIRJ (the Center for Independent Living of Rio de Janeiro), where she currently serves as Honorary President. Ms. Berman-Bieler was formerly Rehabilitation International Deputy Vice President for Latin America, and is editor of several newsmagazines on disability issues.

Rosangela Berman-Bieler is a scheduled keynote speaker at the 1999 TASH Annual Conference in Chicago.

1999 TASH Annual Conference

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The practice of Yoga is an ancient form of healing and fitness for the entire body, mind and spirit. It doesn't matter what your present physical ability or condition is, or what you can or cannot do. There is no competition - as you practice, you will do better and feel better. This is a time of day for anyone who wants to explore peace of mind, and energize yourself for the day through Yoga. We'll also do breathing exercises and meditation.

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Funding, Freedom & Citizenship: The First International Conference on Self-Determination & Individualized Funding

Join us at the Seattle Westin, July 29-31, 2000

During the past decade individualized funding (also known as direct payments or individual budgets) and self-determination have become focal points for the worldwide disability movement. Individualized funding is now recognized as a fundamental requirement for self-determination, enabling people to purchase, and therefore gain control over, the supports needed to enjoy meaningful lives in the community.

In the USA, the Robert Wood Johnson Foundation has funded self-determination projects in numerous states which emphasize the liberty interests of individuals with various disabilities and their chosen family and friends. Throughout the rest of the world, most notably in Canada, the United Kingdom and Australia, a variety of projects using individualized funding are now underway, largely in response to the lobbying efforts of self-advocates and their supporters.

This conference will provide a forum for:

❖sharing experiences and lessons learned from the many demonstration projects and research initiatives that are underway around the world;

❖discussing critical political, policy and implementation issues;

❖participating in international consensus building activities to arrive at a shared view of the fundamental principles and critical components of individualized funding and self-determination; and

❖building collaborative partnerships that will energize the international movement in the new millennium.

Over 1,000 people from around the world are expected to participate including people with disabilities, family members, community advocates, professionals, service providers, researchers, administrators, and government officials. The conference will be rich in opportunity and outcomes, with topics and speakers being sufficiently broad enough to encourage participation from other disability areas including developmental disability, the independent living movement, seniors, and people involved in the mental health movement. Some of the topic areas that will be included in the program are:

- What do self-determination and individualized funding mean?
- How can people who need support gain real control over money?
- What sort of professional involvement will an individualized funding approach need?
- How can effective stakeholder alliances be established?
- What are the major system obstructions that must be overcome?
- Is there a need for community support and service standards?

This will be a very accessible, inclusive, and truly international conference. From the beginning, the core group of planners realized that forming strong collaborative partnerships in the early stages of conference planning would be critical to achieving an international event of significant impact. Currently there are 8 founding organizations and several sponsoring organizations committed to the effort. The conference logistics and program are being developed under the guidance of an international steering group and an international program planning group. For a list of collaborating organizations, for information on becoming a sponsoring organization, or for more information on the conference please contact Denise Marshall at dmarsh@tash.org or visit the conference website at http://members.home.net/directfunding

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The First International Conference on Individualized Funding & Self Determination

July 29-31, 2000 at the Seattle Westin

Preliminary Agenda

Saturday, July 29, 2000
1 p.m. Conference Registration Begins

2 p.m. - 5:00 p.m.
Pre Conference Sessions

Sunday, July 30, 2000
7:30 a.m. Conference Registration

8:45 a.m. - 10:15 a.m.
Opening Plenary
•Keynote speakers will include users of individualized funding from various disability groups from around the world, as well as family members and professionals

10:45 a.m. - 12:15 p.m.
Concurrent Sessions

12:15 p.m. - 1:45 p.m.
Lunch

1:45 p.m. - 3:15 p.m.
Concurrent Sessions

3:45 p.m. - 5:15 p.m.
Concurrent Sessions

Monday, July 31, 2000
8:45 a.m. - 10:15 a.m.
Concurrent Sessions

10:45 a.m. - 12:15 p.m.
Concurrent Sessions

12:45 p.m. - 3:00 p.m.
Lunch and Closing Plenary
•Presentation of conference declaration and closing keynote remarks

TASH NEWSLETTER

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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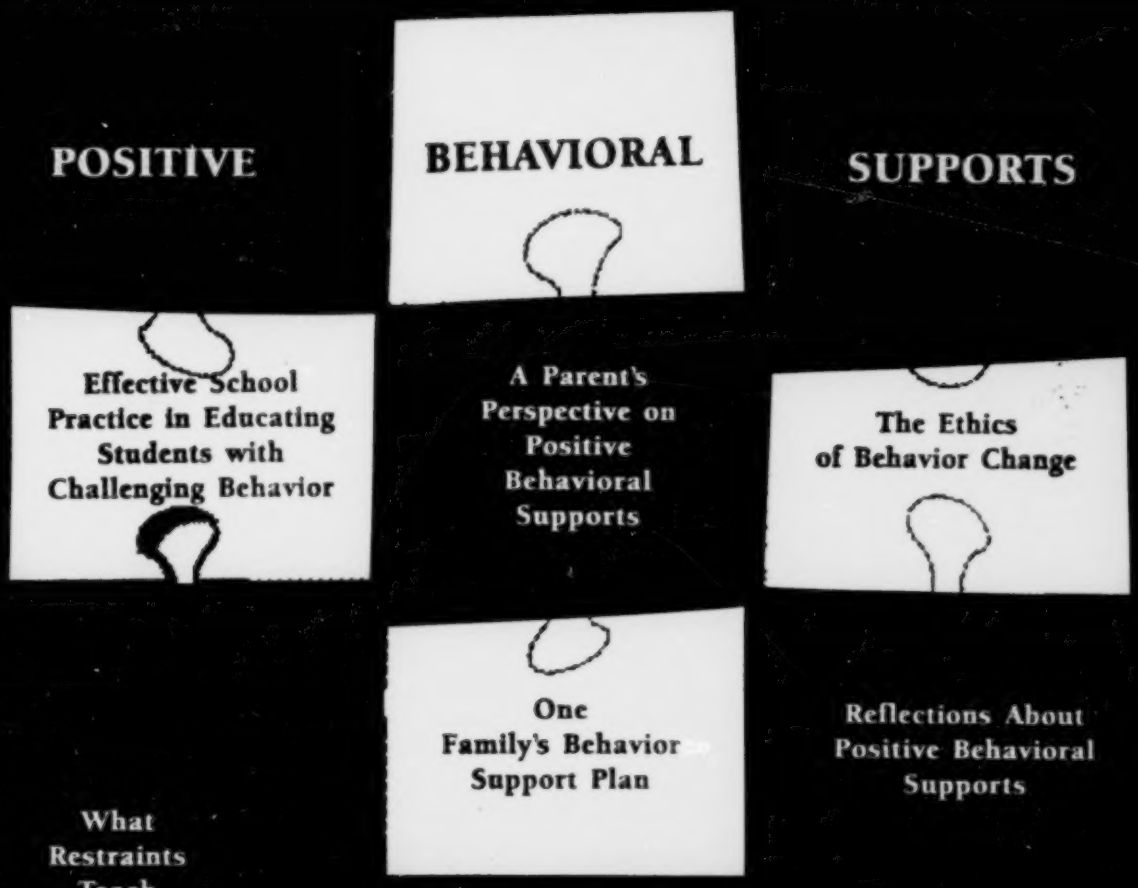
TASH

Newsletter

VOLUME 25 ISSUE NUMBER 11 NOVEMBER ~~MARCH~~ 1999


POSITIVE
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Effective School Practice in Educating Students with Challenging Behavior
A Parent's Perspective on Positive Behavioral Supports
The Ethics of Behavior Change
One Family's Behavior Support Plan
Reflections About Positive Behavioral Supports
What Restraints Teach

Also Inside: In Memory of James Velez and New Resources and Reports on Community Inclusion

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

—

Building communities in which no one is segregated and everyone belongs;

—

Forging new alliances that embrace diversity;

—

Advocating for opportunities and rights;

—

Eradicating injustices and inequities;

—

Supporting research and disseminating knowledge and information;

—

Promoting inclusive education;

—

Supporting progressive legislation and litigation; and,

—

Promoting excellence in services.

From the Executive Director

BY NANCY WEISS

These are dangerous times for people with challenging behaviors. On a regular basis I receive e-mails from parents whose children are being physically restrained in public and private schools. Jean Bowden, a mother from Massachusetts, sent me a videotape of her daughter, Abbie, at school. When Abbie began displaying challenging behavior at home, her physicians recommended that the public school in which Abbie was enrolled video a typical day so that they could see what kinds of pressures Abbie encountered during her day. The videotape they received startled Jean and Abbie's doctors.

In the tape, Abbie who is ten years old, is restrained multiple times throughout the day, each time for a long period of time. The teachers alternately hold her face down on the floor, kneel on her, sit on her and hold her from behind, seated, with her arms crossed in front of her. Throughout, Abbie is crying or pleading, "I ready now," "I sit quiet now," "Ready to sit in seat and fold hands," "ready to be quiet now". The teachers, ignoring her pleas, continue to restrain her. Abbie's transgressions? Participating in a song when it was not her turn, refusing to blow her nose, getting out of her seat and taking a card from another child.

Another mother wrote that she had just learned that her 3-year-old son was being

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Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarsh@tash.org
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From the Executive Director

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We compromise the public's perception of all people with disabilities when our treatment implies that these are dangerous, unpredictable people whose extraordinary behaviors need to be controlled through extraordinary means.

seat belted into a high chair to sit in the dark for 2 1/2 hours daily with no books or toys for "quiet time." I've heard from a myriad of parents dismayed that the program being implemented in school for their young children with autism entails excessive amounts of restraint and physical control. Often the sole point of such programs seems to be to break a child's spirit as one would a wild pony. The message is "Do what you're told - I'm in control and you're not." Is this the lesson we want our children to be learning? *

Today I had a conversation with a young woman from Denmark who is in the United States doing research on abuses against people with disabilities. She was astonished at the widespread use of punishment and aversive procedures in this country. She said, "When I go to third world countries I am not surprised to see terrible conditions but I am shocked by what I am finding here." In Denmark the use of punishment is simply not so deeply ingrained in the culture. One doesn't see parents spanking their children. It is unheard of to physically punish people with disabilities. This young woman had worked in a residential facility in Denmark. She told me that a psychologist from the United States had come to consult with the staff there. He recommended cold showers as a punishment for misdeeds. The Danish staff were horrified.

She asked me why I thought aversive procedures are so widely used here. I told her that in my view there are two forces at work. First, it seems that we have a strongly held ideology that says that people who work hard and do right should get rewarded (the American work ethic) and those who do wrong need to be punished. The roots of such thinking go back to the very earliest days in this country; the Salem witch trials being a one example. Often when I speak with people who work in residential settings or schools, there is resistance to some of the principles of positive behavioral supports. They say, "So we're just going to let her do whatever she pleases? There have to be some consequences for her behavior!" It's hard for people to let go of their need to punish behavior they find troublesome.

The second, and probably more important reason we continue to rely on the use of aversive techniques in this country has to do with people's ability to separate themselves from people with disabilities. If people who are not labeled with a disability viewed people with disabilities as being as fully human and as worthy as themselves, it would be hard to imagine subjecting them to cruelties that are commonplace in some settings. It may be necessary for the people implementing aversive methods to view the people who are the recipients of these procedures as very different from themselves. The implementation of restraints or aversive techniques requires the avoidance of a personal and caring relationship - when that is the very thing that people with challenging behaviors most need in order to change their behaviors.

It may also be important for staff to describe aversive procedures in clinical, detached terms, and to convince themselves that such interventions are necessary to free individuals with significant behavior challenges from their disabling conditions. This depersonalization has a cyclic effect. Such perceptions encourage the continued implementation of demeaning procedures, which in turn results in the further devaluation of the recipients of such methods. We compromise the public's perception of all people with disabilities when our treatment implies that these are dangerous, unpredictable people whose extraordinary behaviors need to be controlled through extraordinary means.

The future is not all bleak. Motivated by the *Hartford Courant's* exposure of the epidemic of deaths while people were being restrained for "therapeutic purposes," many states are introducing legislation to restrict the use of restraints. There are also several pieces of Federal legislation that propose to limit the use of restraints and seclusion (S. 736, S. 750 and H.R. 1313). Finally, the Health Care Financing Administration (HCFA) has introduced new rules to regulate the use of restraints in some facilities. Unfortunately, none of the regulatory language that I've reviewed goes far enough to protect the rights of people with disabilities. Most of these new laws and regulations call for little beyond additional authorizations and reporting.

It must be TASH's mission to move society toward viewing all people, including people with disabilities, as deserving of the same rights and respect as all other people. We use methods against people with disabilities that would not be tolerated if they were used on animals. If word got out that the dogs at the local animal shelter were being trained to be compliant through the use of painful electric shock or that cats were being forcibly restrained for hours on end, there would be public outcry, demonstrations and condemnation. I once believed that people would cease to be subjected to dehumanizing practices in the name of treatment if the public was made aware of these atrocities. I do not believe that any more. The word is out. We know about it; it's been seen on TV, yet the brutality continues. It's time to put an end to these practices - not only because they are dehumanizing but because they are unnecessary.

* *Some of the families who have written to me about their children being restrained have come together to form a new organization called CIBRA - Children Injured by Restraints and Aversives. You can visit their web site at: http://users.1st.net/cibra*

Reflections about Positive Behavioral Supports

BY JACKI ANDERSON

This is an exciting time to be involved with issues related to behavioral supports. I welcome the opportunity to reflect upon the progress we have made over the past 10 - 15 years and the challenges we have yet to overcome. After years of working with individuals whose disabilities included challenging behavior, initially as a classroom teacher and then as an inservice and preservice trainer, I became involved with the first NIDRR funded Rehabilitation Research and Training Center (RRTC) in the area of positive behavioral interventions. The RRTC on Community-Referenced Non-Aversive Behavior Management (1987-1992), a six university consortium directed by Rob Horner, was followed by a second center, the RRTC on Positive Behavioral Support also directed by Rob. Currently, a new RRTC on Positive Behavioral Support (1998-2003) directed by Glen Dunlap is following up and expanding upon the research and training efforts of the first two centers. During the course of these projects there have been changes in policies, practices and the direction of research. My personal frame of reference is related to my role as training coordinator of these Research and Training Centers. It should be noted that these Centers, although extremely productive and effective in furthering the technology and application of Positive Behavioral Support (PBS), are but a piece of the work in this area.

Over a decade ago when the first RRTC began, controversy was raging regarding aversive vs. non-aversive interventions; individuals with problem behavior were likely to be served in segregated schools, residential and work settings. "Behavior" was typically addressed via consequences and behavior interventions were designed and implemented in isolation from other educational or life supports. A double standard existed for individuals with disabilities and the general population. The title of the first Center reflects the need to focus on effective interventions that were "non"-aversive, using standards for acceptability that were referenced against that of the community in general. Despite emerging literature on functional analysis, research at that time typically focused on single element interventions that were rarely designed on the basis of functional analyses. Typically, these studies were not conducted in natural, inclusive environments, and did not address either the long term impact on targeted behavior or on the lives of the people being studied.

The current climate has changed dramatically in several ways. There is a much more person centered approach to behavioral interventions as well as other educational and life supports. There is widespread understanding that "behavior" serves a communicative function and must be looked at in context. Behavioral interventions are comprehensive, multi-element, educational in nature, and based upon functional assessment of the target behavior, the contexts in which the behavior occurs and the overall picture of the life of the individual. Similarly, research on PBS is increasingly longitudinal, includes participants in the research process and typically addresses packages of multi-element interventions. These interventions are based on functional assessments and designed to result in at least the following: environmental modifications, acquisition of acceptable behavior to replace targeted problem behavior, improved communication skills and social networks, increased participation in inclusive schools and communities, as well as other lifestyle enhancements. In addition to changes specific to positive behavioral supports, many of these current practices reflect changes in human services that are more person centered, inclusive, respectful and based on a standard of life as evaluated for a same age peer without disabilities. Changes in behavioral interventions have been influenced by research results, demonstrations of successful inclusion in schools and the community, training and dissemination efforts and persistent advocacy efforts for widespread implementation of PBS. We now use quality of life as a yardstick to develop goals and measure outcomes. State and local policies often require person-centered approaches to assessment and planning. We have even legislated requirements for addressing problem behavior with positive behavioral supports based on functional assessments, and IDEA '97 at the national level and some states have even more stringent requirements (e.g. California and Nevada).

Yes, there is cause for celebration regarding the gains made to date!

The articles in this issue of the *Newsletter* provide wonderful examples of current practices including: a comprehensive process for developing, implementing and monitoring of positive behavior support plans (Knoster & Kincaid; Chapman, Kincaid & Shannon); the need for long-term collaborative teamwork and partnerships with

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Reflections about Positive Behavioral Supports

Continued from page 4

families to develop support plans that are relevant to and effective in the contexts in which the individual spends their time, the complexity of effective collaboration and the positive outcomes of these efforts overtime (Clara Berg; Chapman, et. al.); and the need for a person-centered planning approach to framing positive behavioral supports (Knoster and Kincaid; Chapman, et. al.).

However, as noted in Gothelf, Petroff & Teich's article, as yet, "positive behavior support has not automatically manifested itself in the day to day thinking, planning and pedagogy of most professionals". Furthermore, Amos' article on restraints illustrates the fact that an "emergency response" may still be used as a "standard procedure" for dealing with problem behavior. Weiss' article on the devastating impact this has on the recipients of such intervention is also described. Therefore, along with celebrating our successes, we have a need for continued work in the area of Positive Behavioral Support.

A critical strategy for effecting change is the provision of training. A major component of the RRTCs on Positive Behavioral Support has been the Team Training Inservice Training project (1987-present). This comprehensive inservice effort has established interagency state level PBS training teams in 21 states and supports this national training network to collaborate in keeping abreast of the explosion of information on PBS, sharing successful training and marketing strategies, and generally working together to expand the availability of PBS practices. Extensive experience with the Team Training Model has demonstrated critical characteristics of both the training content and process necessary to achieve ongoing implementation of PBS practices. The training content must address all aspects of PBS including:

- collaboration and team building strategies, including conflict resolution;
- quality of life and person centered planning as fundamental themes underlying positive approaches;
- proactive strategies for preventing the occurrence of problem behavior;
- functional assessment;
- identification and instruction of replacement or competing behavior to serve the function of target behavior;
- curricular, instructional and environmental modifications;
- the development of comprehensive support plans;
- emergency interventions and the distinction between these and ongoing positive interventions;
- a process and strategies for monitoring and adjustment of the support plan;
- strategies for needed systems changes to assure ongoing implementation of positive behavioral supports.

Critical characteristics of the training process include:

- the use of a trainer-of trainers model to increase the number of "experts" at the local level;
- the use of a team training format where teams include the focus individual and the persons/agencies involved in various aspects of his or her life. These teams work together throughout and beyond the training process to design, implement and monitor individualized support plans;
- the use of a longitudinal, dynamic training process where teams are supported in the application of assessment and intervention techniques as a part of the training process.

If your community, school, IEP team, family, agency etc. is considering investing in PBS training or an "expert" consultant, there are a number of questions that can be asked to increase the likelihood of success with these endeavors. Samples of these are noted below:

1. Ask potential trainers or consultants specifically what their philosophy is regarding PBS and the use of aversive interventions.

2. Follow this with a request to see examples of support plans they or their trainees have developed.

3. Ask for references and ask them the same questions.

4. Ask what the trainers'/consultants' experience is with the environments relevant to your concerns(e.g. school, home, work) and how they will assure that support plans will fit with the values and priorities of the "cultures" of these environments.

5. Request information regarding the topics of training. Will it cover all aspects of PBS?

6. Ask for information regarding the training and/or consultation process. Will it include teams and the commitment to collaboration among individuals who may have had adversarial relationships in the past? Will it include supported application of PBS techniques and continue long enough to provide assistance with evaluation and needed adjustments of supports?

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Policies and legislation have set the stage for widespread availability of positive behavioral supports. Our challenge is to take advantage of this opportunity - spread the word, provide training in positive support techniques and processes, assist systems with incorporating PBS practices and values into existing operations, and, where necessary, make use of laws to demand access to positive behavioral supports.

Refections about Positive Behavioral Supports

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Proactive planning and research prior to investing resources in training and/or consultation can help to avoid the all too common but often ineffective one time, one topic training or the consultation of an outside "expert" who is not committed to a PBS model or who is but is unfamiliar with the school, family etc. culture and thus unable to help design PBS plans that can or will be implemented

In summary, tremendous gains have been made, there is a continuing and perhaps even more urgent need at this time to provide training, change systems and generally build capacity at the local community level; capacity that results in the ability of schools, service providers, agencies, families and communities to provide effective supports for an individual over his or her life span. Policies and legislation have set the stage for widespread availability of positive behavioral supports. Our challenge is to take advantage of this opportunity - spread the word, provide training in positive support techniques and processes, assist systems with incorporating PBS practices and values into existing operations and, where necessary, advocate for laws to assure access to positive behavioral supports.

Jacki L. Anderson is Professor and Coordinator of credential and masters degree programs in the area of Moderate/Severe Disabilities in the Department of Educational Psychology at California State Univerity, Hayward. She is Co-coordinator of Training for the Rehabilitation, Research and Training Center on Positive Behavioral Support, and a member of the TASH and Cal-TASH Boards.

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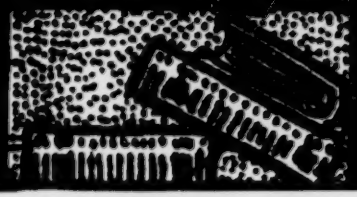
Effective School Practice in Educating Students with Challenging Behavior



BY TIM KNOSTER AND DON KINCAID

Providing educational programs for children who have significant emotional and/or behavioral needs presents a great challenge. This challenge can, at times, appear overwhelming when children who present problem behavior are to be educated within typical school and community settings.

Traditional approaches to "manage" such problems are often ineffective, primarily for two reasons. First, the common application of behavior management in schools has paid little attention to understanding (a) who the student is, (b) what the social contexts for behavior are, and (c) what the function or purpose of the problem behavior is. Second, traditional management procedures have typically placed exclusive emphasis on using unpleasant consequences to suppress or control student behavior, rather than teaching socially appropriate alternative skills.

Experience and the literature suggest that an effective and efficient team-based model for designing and implementing individual student programs is child-centered, multi-component, and based on a functional behavior assessment (Tilly, Knoster, Kovaleski, Bambara, Dunlap, & Kincaid, 1998; Bambara & Knoster, 1995 and 1998; O'Neill, Horner, Sprague, Albin, Storey, & Flannery, 1997). Positive Behavior Support, or Positive Approaches, reflects these principles. Positive Behavior Support is an empirically-based, problem solving approach that matches a set of supportive strategies to the needs of the individual student, his or her family, and others across school, home and community settings.

Positive Behavior Support is based on the belief that problem behavior results from unmet needs. With this central tenet, positive behavior support is guided by four underlying assumptions about challenging behavior and effective interventions:

1. Challenging behaviors are context related.

2. Challenging behaviors serve a function for the student.

3. Effective interventions are based on a thorough understanding of the student, his or her social contexts, and the function of the problem behavior.

4. Positive behavior support must be grounded in person-centered values that respect the dignity, preferences, and goals of each student along with his/her family.

The process of support begins with a functional behavioral assessment in which we identify the environmental influences of challenging behaviors, along with individual student strengths, preferences, and interests. We then customize behavior support plans to address individual needs and life circumstances. Plans consist of multiple interventions or support strategies that emphasize alternative skill training, environmental adaptations, and lifestyle enhancement. Key characteristics of positive approaches are:

- Support is assessment based with interventions directly linked to environmental influences and hypotheses concerning the function(s) of the problem behavior.
- Support plans are comprehensive, usually involving multiple interventions.
- Support is proactive, involving teaching alternative skills and adapting the environment.
- Support emphasizes lifestyle enhancement in inclusive settings as the context for the long-range goal of interventions.
- Support reflects person-centered values that honor the dignity and preferences of the student along with his/her family.
- Support is designed for everyday settings using typically available resources.
- Support plans are collaboratively developed by the educational team in partnership with the student and family.
- Support holds a broad view of success that includes (a) increases in the use of alternative skills, (b) decreases in the incidence of problem behavior, and (c) improvements in quality of life.

Functional Behavioral Assessment

The process of coming to an understanding of why a student engages in problem behavior and how student behavior relates to the environment is referred to as functional behavioral assessment. The purpose of functional behavioral assessment is to gather both broad and specific information in order to better understand the specific reasons for the student's problem behavior. In particular, this type of assessment can provide an Individualized Education Plan (IEP) team with useful insight into (1) why a given student engages in problem behavior, (2) when the student is most likely to engage in the behavior of concern, and (3) under what conditions the student is less likely to engage in the

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problem behavior. IEP teams develop hypothesis statements as a result of the assessment process. Hypothesis statements serve a number of purposes including (1) to summarize assessment results, (2) to offer explanations for the student's problem behavior, and (3) to guide the development of a behavior intervention plan.

There are two common approaches to collecting useful information in school-based programs. The first is known as "informant methods" which involve talking with the student who presents the problem behavior and to those people who have direct contact with, and knowledge about, the student. The second approach is "direct observation" which requires systematic observation of the student within typical daily routines across settings. Typically, IEP teams that employ these two approaches in conducting an FBA (functional behavioral assessment) will derive adequate information from which to formulate hypotheses.

The first stage of functional behavioral assessment is to gather broad information about the student's skills, abilities, interests, preferences, general health, and well being. This type of information typically is gathered through review of existent information and evaluation data, IEP team discussions and interviews, the use of rating scales, and through person-centered planning processes.

In the second stage of functional behavioral assessment, the IEP team gathers contextual information that pinpoints the circumstances/situations that are regularly associated with the occurrence of problem behavior and the function of the student's problem behavior. Basic questions asked during this stage are:

- When is the student most likely to engage in the problem behavior?
- What specific events or factors appear to be contributing to the student's problem behavior?
- What function(s) does the problem behavior serve for the student?
- What might the student be communicating through the problem behavior?
- When is the student most successful, and therefore less likely to engage in the problem behavior?
- What other factors might be contributing to the student's problem behavior?

Hypotheses

As a result of conducting a functional behavioral assessment, the IEP team develops hypotheses. Two types of hypotheses are recommended to guide the identification and selection of child-centered interventions and strategies: specific and global hypotheses.

A specific hypothesis pulls together the specific information gathered during the functional behavioral assessment. Specific hypotheses help to explain why problem behavior occurs by describing both fast and slow triggers (i.e., antecedent and setting events) for the problem behavior and the possible function of the problem behavior.

While specific hypotheses are essential for building effective behavior intervention plans, they alone cannot provide a comprehensive understanding of the student nor the complexity of conditions that might be negatively influencing behavior. Therefore, the IEP team should next develop a global hypothesis statement. A global hypothesis attends to broad influences in the student's life such as the student's skills, health, preferences, daily routines, relationships, and general quality of life.

Behavior Support Plans

Effective support plans consist of multiple interventions or support strategies. This is sometimes referred to as a multi-component plan, which is a technical way of saying that the team is going to do a number of different things within a close time proximity in an agreed-upon manner. This includes preventative, teaching, and reactive types of strategies. Comprehensive support plans comprise (1) antecedent and setting event modifications, (2) the teaching of alternative skills, (3) consequence strategies, and (4) lifestyle interventions. Each of these four component areas work in concert with one another to contribute to meaningful outcomes that are durable over time.

Assessing the impact/outcomes of positive behavior support requires attention to a wider range of variables than simply behavior change. ...this wider range of variables includes "quality of life" or "ecological" outcomes for students with disabilities (e.g., emotional, material and physical well being; interpersonal relations; personal development; self-determination; social inclusion; and exercising individual civil rights and responsibilities).

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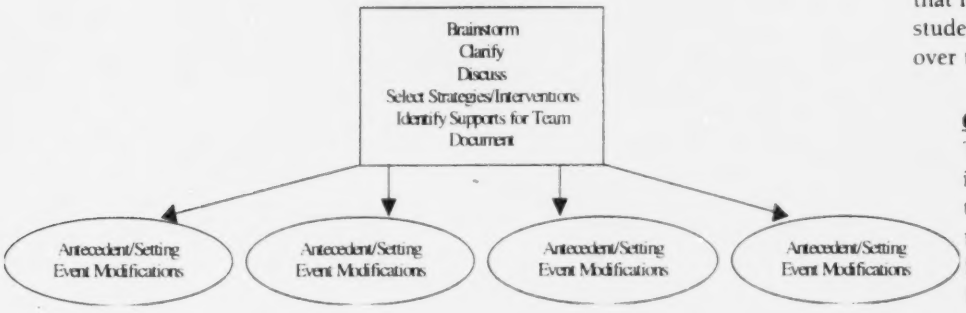
Once hypotheses have been developed by the team, a structured process should be used to identify and select supportive strategies and interventions. The following is a framework that has been utilized by the Tri-State Consortium on Positive Behavior Support.

Example of Positive Behavior Support Framework



While using hypotheses to select interventions will increase the likelihood of success, it is unlikely that any one intervention will be sufficient by itself. This is why multiple interventions are typically required by teams supporting students with challenging behavior.

In total, positive behavior support plans are uniquely tailored to each student's needs, preferences, and long range goals. Effective support plans take into consideration the feasibility (i.e., "doability") of the plan. This is accomplished by collaborating with the student, staff, and family members in the design phase of the multi-component plan to best ensure a good fit across settings and routines. Long- term effectiveness is the result of multi-component support plans that are modified and adapted as warranted over time.

Measuring Progress and Impact

Support plans are effective when they produce meaningful outcomes that are durable. Because problem behaviors can significantly interfere with an individual's quality of life (e.g., relationships, access to preferred activities, inclusion) effectiveness must be evaluated in terms of personally meaningful results.

Behavior change serves as the essential outcome in positive behavior support. However, over the course of the past few years, the field has begun to realize that assessing impact/outcomes of positive behavior support requires attention to a wider range of variables than simply behavior change. For lack of a better description, we refer to this wider range of variables as "quality of life" or "ecological" outcomes for students with disabilities (e.g., emotional, material and physical well being; interpersonal relations; personal development; self- determination; social inclusion; and exercising individual civil rights and responsibilities).

When a behavior support plan is effective, the team will realize increases in new skills, reductions in problem behavior, and progress toward these broader lifestyle improvements. When this happens, your team should ask, "What's next?" Do these gains justify maintaining the status quo, or should the support plan be expanded to enhance further growth?

If progress is not evident, your team should ask, "Why not?" Perhaps the team's hypotheses are inaccurate or the plan does not adequately address the influences or function of the individual's problem behavior. It could be that the plan has been implemented inappropriately, or that other events have hindered positive outcomes. Lack of progress should trigger a reflective review of the plan.

Ultimately, making decisions about the effectiveness of a support plan requires thoughtful consideration. Keep in mind that modifications will be likely as a student's needs and circumstances change over time.

Closing Thoughts

The use of Positive Behavior Support in school based programs continues to gain momentum for a number of reasons. Primary catalysts in the field have been a) the continually increasing body of literature that documents important outcomes for students, families, and practitioners, b) new requirements in IDEA '97, and c) increasing demand in the form of advocacy efforts in tandem with requests for help from practitioners. In response to demand, an increasing number of outreach programs have either been expanded or newly launched across the country (e.g., federally funded projects such as the Rehabilitative Research Training Center on Positive Behavioral Support, the Center for Positive Behavioral Intervention and Support, and the Tri-State Consortium and Regional Collaborative on Positive Behavior Support). Look for future articles in the TASH *Newsletter* that will highlight valuable information concerning the impact of many of these projects.

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Author's Note: *In light of the importance of this topic coupled with TASH's historical stance on support of positive approaches, and in further efforts to be responsive to its membership, TASH will be disseminating via future newsletters a resource listing on Positive Approaches. In particular, this listing will highlight the names of leaders in the field who have agreed to serve as state and/or regional contacts concerning outreach on PBS. Until this listing is ready for publication, TASH members interested in learning more about Positive Approaches are encouraged to check out the following Web Sites on the Internet:*

Tri-State Consortium on PBS
www.wvu.edu/~uacdd/tspbs/

Rehabilitation Research Training Center on PBS
www.rrtcpbs.org

Center on Positive Behavioral Intervention and Support
www.pbis.org

Tim Knoster and Don Kincaid are collaborators on the Tri-State Consortium and Regional Collaborative on Positive Behavior Support, both federally-funded outreach projects through the U.S. Department of Education's Office of Special Education. Together they have published manuscripts and training materials concerning the linkage among research, policy, and practice in positive behavior support, person-centered planning, wrap around, and inclusive reform in schools and communities. You can reach either of them by contacting Tim Knoster at tknoster@csiu-pa.org

Introducing the Youngest Members of TASH's Central Office Staff!

The (young) kid of TASH at our Summer Pool Party: *Clockwise, from top left: TASH Board member Jorge Pineda's nephew, Daniel; former staff member Marcie Roth's son, Dustin; Kelly Nelson's son, Adam; Nancy Weiss' daughter, Kelsey, Denise Marshall's daughter, Jessica; Dan Dotson's son, Matthew; Denise's son, Joshua; Kelly's son, Stephen; Dan's son, Tim; and Kelly's son, Mike.*

Missing from this photo: Marcie's daughter, Jessica, Kelly's son, Ben; Rose Holsey's children Douglas, Stacey, Keith and Lauren; and Mary Bellone's children Mary, Stephanie, Nicholas and Kyle.

and welcome to our newest addition, little Grace!

Grace with her mom, Priscilla Newton

THE MARKETEERS:
A Parent's Perspective on Positive Behavioral Support

BY CLAIRE CHAPMAN, Parent,
DON KINCAID, University Affiliated Center for Developmental Disabilities,
and
PATRICK SHANNON, Virginia Institute for Developmental Disabilities

For the past several years, families, consumers, school and agency staff in Pennsylvania, Virginia, and West Virginia have benefited from the activities of the Tri-State Consortium for Positive Behavior Support. The agencies involved in this collaboration have been committed to a philosophy that includes providing person-and family-centered support, emphasizing a broad ecological approach for behavior support, committing to a team approach, emphasizing positive and effective supports for all children, and, increasing local capacity. The Tri-State Consortium has a shared commitment to family, school and community collaboration as well as a commitment to disseminating an empirically-based problem solving process for positive behavior support that addresses five broad questions. In this article, one parent, Claire Chapman, addresses those five questions and comments on the impact that positive behavior support has had on herself, her family, her son, and his team.

Claire's Story

"My name is Claire Chapman. My husband Bob and I make our home in Stafford, Virginia with sons Mark, age 20 and Brian, age 16. I'm a homemaker who does some volunteer work including serving on the Stafford County Public School's Special Education Advisory Committee (SEAC). Mark is a student at Brooke Point High School where he continues to flourish. Mark works two periods a day in the school's library and does most of his academic lessons independently. His school day will now include job exploration. At home, his self help and independent living skills enable Mark to do things for himself with minimal supervision. We credit Mark's on-going success to the opportunities afforded us through Person Centered Planning and Positive Behavior Support (PBS) training. This training enabled us to explore the various techniques that would help Mark to handle changing situations and environments. We were also encouraged to ask lots of questions and to expand Mark's horizons. Our family also is fortunate to have an extensive support system that offers constant encouragement. Our family is grateful for the chance to have taken part in Person Centered Planning and Positive Behavior Support training. It has truly made a difference in our lives."

Question 1- Establishing collaboration: *How do we form a strong partnership among parents, professionals, and the community?*

Claire's Response: "In our situation, Mark had a behavior problem that was becoming excessive and would surely get in the way of Mark succeeding at school. We had a definite need to get some sort of help. At this point, the Virginia Institute for Developmental Disabilities was offering Positive Behavior Support training in our county and we were selected to be a part of this training. A group was formed that included people in Mark's daily life who would be familiar with the behavior of concern. My husband and I, his teacher, speech therapist, a transition specialist, a representative from the local Community Services Board, and a classroom aide were all invited to be a part of this training. The county school system offered the opportunity to participate in this training to others, as well, in order to build capacity. The county school system felt that others could benefit and learn about PBS by participating in the training. They could then take this new knowledge and apply it to individuals in other settings.

...families value the development of a trusting collaborative relationship with their positive behavioral support teams. They feel there are other individuals who can understand them and on whom they can depend to assist them in accomplishing important goals in their lives and their child's life.

While we would focus on Mark's particular targeted behavior, the knowledge gained from our training could be adapted to anyone else's individual

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The Marketeers: A Parent's Perspective on Positive Behavioral Support

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situation. This group that came together for the training soon became known as 'Mark's Team' and later the 'Marketeers.'

I think that one of the keys to parent and professional collaboration was creating an environment for open communication. It was very clear to me right from the beginning of the process that we were a team. The PBS trainers communicated to me that I was an equal member of this team and that the team was going to work closely to support Mark and our family. It was also communicated that everybody on the team needed to be open and willing to share information. I felt free to ask questions and was never made to feel dumb. The major concern the PBS trainers had was whether or not I understood what they were telling me. Again, I think that the person-centered planning process helped build some trust between us.

Team trust was tested right from the start. The school system was being a little rigid about committing staff time to the process. The team came together to advocate with the administrators to release staff to participate in the process. This was no small accomplishment as this meant that the school system had to pay for substitute staff. Another thing we did, was meet in Mark's school so that it was easier for his teachers to attend. It also helped because it allowed other team members who did not work with Mark in the classroom to observe his class."

Question 2 - Broad Assessments of the Child and Family Environment: *What strategies can assist the team in getting to know the child and family better?*

Claire's response: "We were already a team before we began the PBS process. We were a good team and we worked well together because we went through the person-centered planning process before PBS. For me, conducting Mark's PATH was essential. They asked me to describe any problems that Mark was having that could get in the way of Mark's success in life, and we put them on his PATH. PBS was mentioned as an approach on Mark's PATH.

When the team first came together, we went through various exercises to 'break the ice'. For me, it soon became apparent that we were all coming together on the human level. We were all going to go through the PBS training as a team, with the goal of addressing Mark's needs. Whatever predetermined views I may have had, for example, that I should never question what the teacher or another professional was suggesting, needed to be set aside. I became an equal partner and my voice was equally as important to the team as the voice of other team members. I realized that these people wouldn't judge me by what I would tell them. I needed to feel safe in telling them everything and in letting them observe me and my family closely. I needed to be honest with them and relate times when Mark's behaviors were at their worst. The more knowledge they had of Mark and our family, the more helpful they could be."

> Mark is just a happier person now. I think that is the best measure of the success of a comprehensive behavior support plan.

Question 3 - Conducting Specific Assessments through Direct and Indirect Functional Assessment Approaches: *What are some practical approaches for conducting functional assessments of the child and his or her environment?*

Claire's Response: "The PBS process can be very long and detailed. Parents, however, need immediate help. Parents want to see results right away, so, just talking about the long-term benefits of PBS may not be enough. I think families need to hear that things are going to improve immediately. One way to do this would be for families to talk with other families about their experiences. I try to talk with other families every chance I get. It helps me and I know it helps them.

Probably the most important approach would be observation. For us, observation came in various forms. We would record (in a journal) what we observed when the negative behavior was present. We could then compare how we saw the situation to how others saw the same exact situation. Another way to observe was by recording our observations right down to the smallest details. We were very specific in recording the events surrounding a particular incident. We would include how Mark's demeanor was at the time, if there were any others present at the same time, and any other environmental factors that could have affected the behavior.

With Mark, comprehensive note taking was put in place. When a problem behavior was observed, a behavior chart was completed, which related the setting, who else was present, antecedent behaviors, and consequence of the behavior. In addition to observations, consistent data collection was the key for our team. Whoever was a constant in Mark's life was asked to help us and we readily accepted their cooperation. For example, if the bus driver saw something negative, she would contact us. Likewise, if something positive occurred, we always welcomed those comments, too. When Mark visited with his aunt, she reported a behavior that was easily redirected and an "incident" was avoided. It was a team effort that went beyond the immediate team.

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A strategy that proved both useful and problematic was using a journal to record Mark's behaviors. Right after a behavior incident, I would write down everything that happened before, during, and after it occurred. This relieved some of the pressure of having team members in my house observing everything I did. I was able to diligently record everything that happened and communicate it to the rest of the team. It wasn't always easy for me to do and it required a lot of training,

Flexibility on our family's part and on the part of the positive behavior support team was essential. To make the plan work, I had to be willing to let people into our home, think critically about being a parent, and change my schedule when I needed to. The team had to be willing to live by rules. ...I believed in what we were doing, but that didn't mean I wanted our lives turned upside down.

but I found it useful. I wasn't the only one who wrote in the journal. Mark's teachers did as well. In this way, I could communicate with them and they could communicate with me on a daily basis about how Mark was doing. If he had an incident at school, I would know about it. I liked this because I felt like I had a better sense of what Mark's day was like and that... surprise, surprise, most of the days he did not have any problems. There was, however, a major problem with the journal. Mark knew what the journal was for. If he did have a bad day at school, he knew that his teacher would write in the journal and send it home with Mark. Well Mark didn't want to get in trouble twice for one incident so he became obsessed with the journal. He wanted to know what we were writing. So we turned it around and asked him to write in the notebook when he had a bad day. This worked so well, that when he had bad days, he wanted to come home and read to me what he wrote in the journal. Short of putting a camera on my head, I think the journal was the best way to collect the information the team needed."

Question 4 - Combining Broad and Specific Assessment Information into a Comprehensive Positive Behavior Support Plan: *How does a comprehensive behavior support plan fit into the child's home, school, and community?*

Claire's Response: "With the complete cooperation of all those directly involved with Mark, we have been able to relate what we have found to be effective ways to help Mark with his behaviors. Those new to Mark's environment were informed of the best ways we found to help Mark perform to his full potential. We have always reminded ourselves that our aim is to 'set Mark up for success.' We were able to show through our comprehensive record-keeping what worked in the past and what we should continue to keep in place. We were always ready to adjust or initiate new methods of handling various situations. We always kept in mind that what didn't work before may be helpful now, and what was already in place may need to be re-evaluated.

Flexibility on our family's part and on the part of the team was essential. To make the plan work, I had to be willing to let people into our home, think critically about being a parent, and change my schedule when I needed to. The team had to be willing to live by rules. I wanted their help and I believed in what we were doing, but that didn't mean I wanted our lives turned upside down. They respected that and we never ran into any issues. I think that is because we were able to be open and honest with each other."

Question 5 - Evaluating and Revising the Positive Behavior Support Plan: *How do I know if the plan is working?*

Claire's response: For me, I can say that I regularly need to remind myself of the outstanding progress Mark has made. I see how he easily handles a stressful situation, where before he would have exhibited challenging behavior. Our home environment doesn't contain the stresses of before. Before, we almost never knew when a behavior would present itself. We learned one way to deal with the unexpected was to better prepare Mark the best we could. Change was never easy for Mark and he did best when his routine stayed the same. But we needed to help Mark adjust to the possibility that perhaps our plans might abruptly change and that everything would be okay anyway. We said things like "I'm not sure when we will get there" or 'we will see what happens" or "maybe tomorrow." Mark is now able to accept when we have to tell him that our plans have changed or if he is asking for something in particular and we don't have it, he is satisfied with something else. He has surely made strides in adjusting to changes in his home and school environment. We have learned how to speak to Mark and how to calm him when the change doesn't always come easy. We use reassuring words to let him know what a wonderful job he is doing and how well he has handled a new or different situation. We allow ourselves the choice to not do something if we feel it might be too stressful. Mark is just a happier person now. I think that is the best measure of the success of a comprehensive behavior support plan. Mark has done most of it on his own. He has matured and he is more independent. I have changed too. I now have the ability to analyze a situation to prevent a behavior or to look at what went wrong. It is a skill that was taught to me and that has changed how I think about Mark's behavior. Another way to assess the success of a comprehensive plan is to imagine what the behaviors would be like if nothing had changed. I am sure that Mark would not be doing this well. Not too long ago I

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ran into someone who knew Mark when his behaviors were at their worst. She was stunned at how good he was when she saw him. She only knew Mark in terms of his behaviors and now she knows Mark for who he really is."

Summary

Claire's story emphasizes many of the issues commonly encountered in the process of developing a comprehensive Positive Behavior Support Plan. As a result of positive behavior support activities across our three state region in the Tri-State Consortium for Positive Behavior Support, we have observed tremendous positive changes as chronicled by families, classroom teachers, and school, community, and agency staff. Additionally, we have been fortunate to document changes in systems when the approach becomes embedded within training, consultation, teaching, and support. It has become increasingly commonplace across the hundreds of teams we have supported to see situations where individuals not only show significant reductions in their challenging behavior, but also learn more effective and appropriate alternative behaviors, develop true friendships, spend more time in inclusive settings, and make many more choices about their personal and educational lives.

In the same way, families value the development of a trusting collaborative relationship with their PBS teams. They feel there are other individuals who can understand them and on whom they can depend to assist them in accomplishing important goals in their lives and their child's life. They also are supported in developing social and personal relationships that are of value to them in dealing with the stresses, frustrations, joys, and celebrations that come with being a parent.

Finally, as Claire's story highlights, parents become much more effective advocates and learn how to thrive within their own support structures, as well as to provide support to other parents of individuals with challenging behavior.

Special Note: This article will appear in a full length chapter in the book, *"Families and Positive Behavioral Support: Addressing the Challenge of Problem Behaviors and Family Contexts,"* edited by Joseph Lucyshyn, Glen Dunlap, and Richard Albin and published by Paul H. Brookes Pub. Co.

Claire Chapman, Parent; Don Kincaid, University Affiliated Center for Developmental Disabilities; Patrick Shannon Virginia Institute for Developmental Disabilities.

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Heard about the recently released special issue of JASH devoted to Interventions for Young Children with Autism? Haven't ordered additional copies yet? Don't delay! Supplies are limited.

To order copies of the Fall 1999 JASH highlighting a range of best practices in educational interventions, call the TASH Central Office at 1-800-482-8274, send an e-mail: jash@tash.org, or visit our web site at www.tash.org/publications/jash/special_issue.htm

❖ **Available from Options in Community Living**

website: www.optionsmadison.com

Celebrating the Ordinary: The Emergence of Options in Community Living as a Thoughtful Organization

By John O'Brien, Connie Lyle O'Brien, Gail Jacob, 1998, $25

A way to think about support living that collects stories, pictures, documents and policies from Options and reflects on their practical meaning:

●emergent order ●autonomy and support lead to liberation ●conflict clarifies beliefs ●high ideals grounded in daily demands ●stretching the ordinary ●acknowledging difficulty ●cultivating expertise ●relationships as resources ●make funding flexible ●temptation to standardize ●learning as a matter of the heart ●chewing on intractable problems●nine enduring understandings●

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Edited by John O'Brien and Connie Lyle O'Brien, editors, 1992, $20

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A Death in Restraint

BY DICK SOBSEY

I read about it in the newspaper. It's too bad about all those people who died in restraint, but what can you do?

One hundred and forty-three of them. Some of them were crazy. Some were retarded. Every one of them was disruptive. Behavior like that needs to be controlled. A lot of them were old people; some were just children. Some parent's heart must be breaking, but will anyone else remember? I know it's a lot of deaths, but some of them happened quite a long time ago.

One of them was in his 30s. I can't remember his name. They say that he was delusional. At times he had hallucinations. He became disruptive and noncompliant. It was really getting out of hand. He was starting to get the others upset and they were starting to act out, too. He needed to learn that behavior has its consequences. So they applied a form of four-point restraint.

Postural asphyxia they called it. That was the cause of death. Sometimes it happens quite quickly, sometimes, it takes a long time. Gravity and exhaustion take over. Drugs, dehydration, shock, or low muscle tone can speed it up. In his case it took three days.

Three days is a long time for anyone to be in mechanical restraints. They should have known better; he wasn't the first person to die in that form of restraint, but I guess it was partly his fault, too. He was just too stubborn to give in. If he had only said that he was sorry, they might have let him out of restraint a little sooner. Maybe he was just too out of it to know what was good for him. They said that he was still hearing voices right to the end. Anyway, it's too late now. Its unfortunate, but these things happen sometimes, and I guess you can't make an omelet without breaking a few eggs.

Even though it happened a long time ago, this became a real famous case. People still remember it and talk about it today. The form of four-point mechanical restraint they used back then was particularly bad for postural asphyxia. He was one of the first ones to die in restraint 2000 years ago.

His parents' hearts must have broken, too, just like the parents of the others who shared his fate in recent years. I guess when we think about him at Christmas and Easter, we should think about all the others who died in restraint like he did. No child of God ever should have to die like that.

The author, Dick Sobsey, can be reached by e-mail at <dick sobsey@ualberta.ca> *Copyright 1998. May be reproduced and distributed without revision for noncommercial purposes.*

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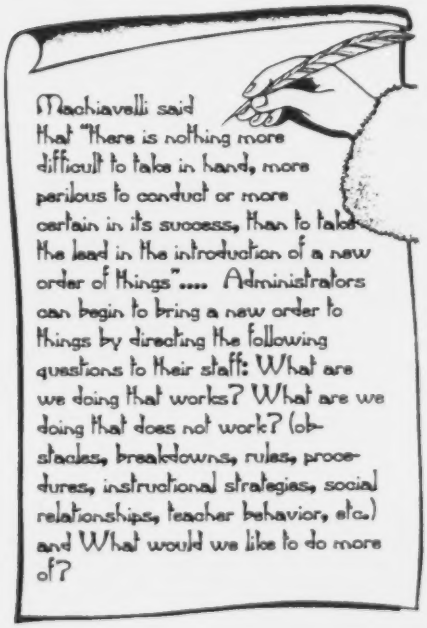
Positive Behavioral Support: Making It Happen

BY CAROLE R. GOTHELF, JERRY G. PETROFF and JENNIFER TEICH

This article is dedicated to Adam, Eileen, Kevin, and Jeffrey who, along with scores of students and instructional staff who have passed through our programs, have made for themselves a place in our heads and hearts in the collective struggle to implement what is right and good.

Although it may be ingrained in people's consciousness and codified in law, positive behavioral support has not yet automatically manifested itself in the day to day thinking, planning and pedagogy of most professionals. Too many professionals have been teaching "the old way" for too long to simply change course because we all agree it is the right thing to do, or because they have taken workshops or participated in inservice training programs. Too many new teachers are uncertain of their positions within a school. They may be too focused on gaining and maintaining control of their classrooms to worry about implementing new methodologies that are not part of the instructional practice of the school. Too many administrators feel compelled to remove or contain the most noncompliant students in the interest of maintaining order, maximizing the efficiency of the school organization and maintaining a stable environment.


Machiavelli said that "there is nothing more difficult to take in hand, more perilous to conduct or more certain in its success, than to take the lead in the introduction of a new order of things".... Administrators can begin to bring a new order to things by directing the following questions to their staff: What are we doing that works? What are we doing that does not work? (obstacles, breakdowns, rules, procedures, instructional strategies, social relationships, teacher behavior, etc.) and What would we like to do more of?

Readers of this article probably agree that positive behavioral support is an effective methodology, that it is a way to achieve a quality of life, and that it is ethically and pedagogically correct. What is right and good is also the most effective practice. Nonetheless, you can still walk into many schools today and hear the following refrains: "Children need to learn that their actions have consequences"; "Children need to be taught that they can't get everything they want"; "They have to be taught to follow the rules"; or "They need to follow the schedule". These catchphrases, beliefs, and attitudes summarize our reflexive reactions to people and situations that frighten us, that make us feel out of control, or that we do not understand. These responses, in turn, shape organizational processes, practices, activities, and serve to define the principles that define the organization. The results may be a school bureaucracy which espouses the rhetoric of Positive Behavioral Support but is incompatible with the philosophical foundation and practice of positive approaches for people with difficult behavior (Lovett, 1996).

In a field that has undergone continual transformations since the early 1970s, the questions remain: How can we support the structures and skills that enable school administrators and instructional staff to stop thinking, managing, organizing, planning, and teaching mechanistically? How can we stop acting as if a professionally structured system of control is a rational and just response to students with difficult behavior? (Evans, 1991; Gothelf & Brown, 1998; Lovett, 1996; Skrtic, 1991).

Difficult ethical dilemmas arise when good ideas are incomplete. We have learned that implementing positive behavioral support cannot be done simply by adding it to the traditional service model through the regulatory process, or by writing a few more chapters in a curriculum guide. It requires us to take a hard, critical look at our organizations and ourselves. In that spirit, this article is not about the methodologies of positive behavioral support, but rather on the implementation of a paradigm. Following are two closely linked elements, each of which makes a unique contribution to the implementation of positive behavioral support. They are offered in recognition of the difficult job faced by teachers and administrators determined to look at themselves and examine the structure of their programs. "It is easy to complain about the shortcomings of the [educational] system...the harder task for us is to imagine what would be better, and then to promote, organize, fund, and structure effective responses" (Mount, 1997, p.53).

Element 1: Administrative support and staff empowerment. A major reason for changing students' behavior patterns is to provide them with a wider range of options within society (Horner, O'Neill, & Flannery, 1993). Mount (1997) points out that when people are inspired by a vision, they work hard to make it happen. Teachers who feel that they have no options and few choices are

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Positive Behavioral Support: Making It Happen

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in no position to support the development of a vision for meaningful life style options for marginalized students. They cannot implement positive behavioral support when they are confronted by educational policies that are based on generic schoolwide prescriptions and are dependent on universal compliance. Administrators demonstrate their commitment to positive behavioral support when they recognize and acknowledge the impact that the immovable aspects of bureaucracy, hardened by standardization and rigidity imposes on teachers and students (Mount, 1997).

There are no simple strategies for changing the bureaucratic obstacles that constrict our ability to respond to people and to implement positive behavioral support. However, administrators can begin this process by 'letting loose the reins of power' and establishing a structure for feedback within the organization (Mount, 1997). Teachers and support staff become organizational stakeholders, by identifying ways that their school needs to change to support new directions.

Machiavelli said that "there is nothing more difficult to take in hand, more perilous to conduct or more certain in its success, than to take the lead in the introduction of a new order of things" (Ledeen, 1999, p. 19). Administrators can begin to bring a new order to things by directing the following questions to their staff: What are we doing that works? What are we doing that does not work? (obstacles, breakdowns, rules, procedures, instructional strategies, social relationships, teacher behavior, etc), and, What would we like to do more of? (Gothelf & Mercer, 1996). Mount (1997) enhances this process by suggesting that stakeholders identify concrete ideas that put forth better alternatives, identify what they need from administrators, and suggest action steps that administrators can take. Remember, change is complex, and sorting through choices for change takes time.

Element 2: School - level collaboration and collegial relationships. The most important priority should be changing the culture of the organization by developing its constituency. Placing these goals first develops the school's capacity for implementing positive behavioral support and making effective changes. The purpose of goals is to focus our attention. The mind will not reach toward achievement until it has clear objectives (Almony, 1994). It is then that the switch is turned on and the magic begins. Administrators and instructional staff become a council of leaders with a shared vision willing to work together to improve the goals of the organization (The Effective Schools Committee, 1994). Remember that good ideas are not adopted automatically, they must be driven into practice with courageous patience.

We must provide teachers with opportunities to develop trusting collegial relationships so that they can reflect on their beliefs about supporting students with difficult behavior and work through the feelings that inhibit their ability to change (Sage & Burrello, 1994). By supporting each other, teachers can relieve the stress associated with change and can share ideas to make the tasks less overwhelming. We need to move from external "expert" staff development programs to internal shared professional development; from teacher isolation to teacher collaboration and mutual support.

Positive behavioral support takes planning. To find much-needed planning time see if schedules can be juggled if teachers can be relieved by support staff, or if classes can team up. The processes elaborated in the first element will generate these kinds of ideas.

So we have come full circle. It is time to celebrate. The school change necessary to support students with difficult behaviors takes incredible energy, time and commitment. You have begun a great and awesome undertaking. It is not an easy journey, and it is important to take time to rejoice in accomplishments and consensus. By celebrating we renew feelings of self-worth, and rise to meet the challenges of continued school improvement.

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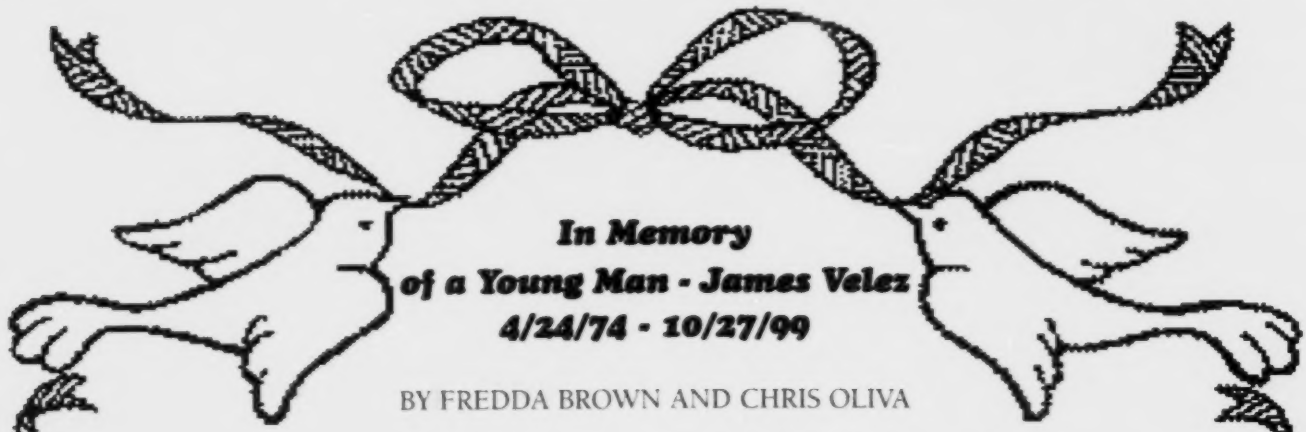


In Memory of a Young Man - James Velez 4/24/74 - 10/27/99

BY FREDDA BROWN AND CHRIS OLIVA

We first met James in 1994 when he was 20 years old. As we sat outside in the cold (he was afraid staff would tape our conversations if we stayed indoors), he said he wanted more than anything to live in New York near his parents, sister, and his many, many loving relatives. Although he was living in a well-kept suburban home on a quiet street, he received a variety of aversive therapies, including hundreds and hundreds of contingent electric shocks. The aversive treatment model was planfully carried over between home and school. His "positive reinforcement" program included earning points that were exchangeable for social interactions, phone calls to his family, and normally prepared food (versus nutritionally correct but tepid, bland, pureed food).

This meeting was in a professional context-but it took not an instant before we knew that he would become a friend— and a teacher. It took not an instant before we saw his humor, wit, charm, spirit, and of course, those big sparkling dark eyes. We marveled as James explained and critiqued his contingency management plan -- with more insight than most professionals with formal behavioral training. We knew at once that James would touch our lives, and our family's lives, forever.

When James finally returned to New York he (disgracefully) was temporarily "placed" in a state institution where he remained for about two more years. Here, there were no "aversives;" but also there was no dignity, nor humanity. The hundreds of thousands of dollars previously available to "therapeutically" punish him while he resided out-of-state, were suddenly not available to support him in a humane fashion in his own community. Somehow, the outrageous cost of aversives could be easily approved and justified, but the cost of humane support required much more approval and justification. While some bureaucrats mechanically shuffled papers to secure the necessary approvals, James lived day after day in an environment not fit for people. Inquiries as to how this situation could possibly exist resulted in empty, bureaucratic responses. No one person would ever take responsibility; it was the "system" (e.g., the budget cap; the time in the fiscal year; the paperwork; the holdup in another department; the upcoming holidays). But.... who makes up a system? Someone somewhere makes decisions. How many empty words of excuse and regret were spoken to James in his life?

After an inexcusably long time, James finally moved to an apartment near his family — fulfilling his life long dream! He accomplished much- he started to learn to drive, to visit people, to have visitors at his place, and to learn to think like a free man; no easy task for a person who spent so many years in coercive situations. James wowed an audience when he spoke at the 1997 annual TASH conference in Boston (perhaps his first visit to Boston without shock devices attached.) Finally, James got to say "no" and "yes" in his life and have these words mean something. He could choose to take risks, and succeed as well as "mess up" as do people not labeled with a disability.

James taught us that it takes more than just good ideas or good intentions to live a self-determined life. It takes a full range and depth of efforts woven into a delicately balanced mosaic to facilitate a dignified and autonomous life. But at this point in time, the mosaic for people like James is too fragile -- too easy to damage it and to break it. If it takes only one budget cut or the signature of one person to destroy the vision and the dream, then we have not truly succeeded -not yet. How much of James' life and death was affected by a system out of balance?

James had a gift, an ability to see through people, and know if they were warm and loving souls, or sense if they were not worth knowing. And when he knew they were warm and loving people, he would quickly and honestly embrace them in his own personal way. And when he embraced you, you felt privileged by the purity of his feelings.

It is amazing how many people were supposed to be "teachers" of James. What really happened to us was that James became our teacher. He taught us about love, persistence, strength, good will, and sincerity, as well as the value of our dreams. He will be our teacher and friend always and he will be in our hearts forever.

It May Be Non-Aversive, But Is It Non-Coercive?: The Ethics of Behavior Change

BY NANCY WEISS

The technology of behavior modification is ethically neutral. It can be used by villain or saint. There is nothing in a methodology which determines the values governing its use. (B.F. Skinner, 1971)[1]

I am concerned that those of us who would never use painful or humiliating techniques to change the behavior of the people we support fail to consider the potential ethical issues inherent in our work. It is as if we believe that if we are not doing things that are by their nature inhumane, we are necessarily acting humanely.

Our first response in encountering a difficult behavior should not be to ask "how can we apply technology to reduce this behavior?" Rather, initial responses should focus on meaningful, collaborative attempts to determine the nature of the distress the person may be communicating through his/her behavior and practical changes to the nature and quality of the person's life.

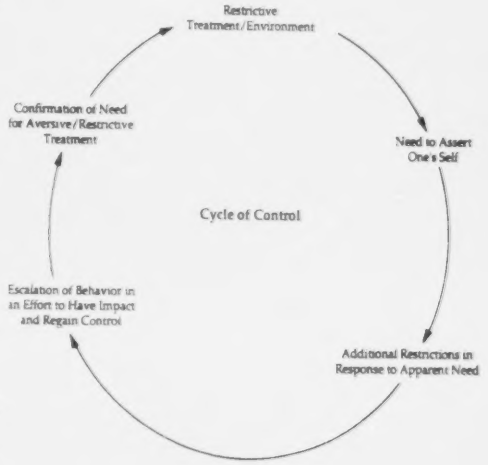
The late Herb Lovett is credited with coining the term positive approaches. In the spirit in which Lovett intended the term, it is important to recognize that every approach that does not rely on aversive procedures is not by default a positive approach. Positive approaches are only those which enhance a person's life - they are characterized by collaboration versus control and focus more on illumination (or understanding the meaning of the behavior from the individual's point of view) than on elimination (or reducing behaviors we perceive to be difficult or unacceptable).

There is no question that some people with disabilities have behaviors that are dangerous or seriously disruptive. I am not a person who believes that because all people are to be valued and respected equally that all behaviors are equally acceptable. Some people (both with and without disabilities) exhibit behaviors that interfere with the quality of their lives and the lives of the people with whom they interact. We have a responsibility to offer supports for people to change behaviors that are dangerous, disruptive or interfere with their ability to achieve their goals for themselves. Our responsibility, however, is to do this in ways that value, enhance and include people.

Many ethical problems in the design and implementation of behavior programs relate to issues of control. Whenever one person is trying to change the behavior of another there is an inherent imbalance of power. People with disabilities are often denied opportunities to make basic life choices and are subjected to unreasonable amounts of control as a matter of course.

Last May the *Hartford Courant* documented over 150 recent cases in which children or adults with disabilities died while being restrained. The case histories read like a catalogue of power struggles. One man's behavior escalated after he had asked to watch television and was told that TV was not allowed during the day, another man became upset after he was denied access to the bathroom, a woman died for the crime of not being willing to hand a family photograph over to staff. While these cases represent the worst imaginable result, power struggles such as these are commonplace. Institutional, community and educational service systems are often designed to restrict freedom of choice.

When power is taken from someone, it is a natural response for him/her to act to reassert control. When people respond in frustration, their behaviors are interpreted as signaling the need for even more restrictive environments. Rather than difficult behaviors being viewed as an indication to re-think the necessity for restricting people's right to self-determine, they are often viewed as signaling the need for even more stringent controls. Behaviors escalate further in response, and the cycle goes unbroken, often until tragedy results, if not in loss of life, surely in the loss of quality of life.


Restrictive Treatment/Environment
Need to Assert One's Self
Additional Restrictions in Response to Apparent Need
Escalation of Behavior in an Effort to Have Impact and Regain Control
Confirmation of Need for Aversive/Restrictive Treatment
Cycle of Control

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It May Be Non-Aversive, But Is It Non-Coercive?: The Ethics of Behavior Change

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Despite the progress we have made in eliminating aversive programs, this unfortunate cycle still operates in programs that seek to control too many aspects of people's lives. No one emerges victorious from such power struggles.

Though it can't be argued that need is the mother of invention, it is also true that invention is the mother of need. None of us needed cell phones, fax machines or e-mail fifteen years ago - now that they exist we don't know how we could live without them. We become addicted to using what we have; what we know. In the same way as we have become addicted to the technology of electronic communication, we have become addicted to the technology of behavior modification.

Positive approaches are only those which enhance a person's life -- they are characterized by collaboration versus control and focus more on illumination (or understanding the meaning of the behavior from the individual's point of view) than on elimination (or reducing behaviors we perceive to be difficult or unacceptable).

We have to be careful that the systems in which we work do not encourage over-reliance on behavioral interventions. In architecture, the rule of thumb is "form follows function"; in human services it is "form follows funding". When funding sources and administrators expect quick resolution of unpleasant behaviors, we deliver. New requirements of IDEA '97 means the use of Positive Behavior Supports in school-based programs continues to gain momentum. See Knoster and Kincaid's article on Effective School Practice in Educating Students with Problem Behavior beginning on page 8 of this *Newsletter*. While this is an important and positive trend, over-reliance on any behavioral technology can result in a failure to view people's behaviors as valid and acceptable.

We are often so ready to identify the behavior, isolate its characteristics, measure it, and design a program to reduce it that we forget to ask the basic questions we would hope someone would ask of us, were we limited to asserting ourselves through our behaviors. These are questions such as:

✔ Who is this person?
✔ What important needs are unmet for him/her?
✔ What would he/she change about his/her life?
✔ What has changed about his/her life that may not have been consistent with what he/she would have chosen?
✔ With whom does he/she have meaningful relationships?

It is important that we answer these questions to unlock the secrets behind the behaviors. If we could offer people more meaningful lives, many difficult behaviors would resolve themselves. Clearly, many of the people we support can't easily articulate answers to questions like the ones above. Likely this is the very reason they resorted to extraordinary behaviors as a means of self-expression in the first place. Often, however, the people who know the person best can come up with some plausible theories worthy of further exploration. When the people who work with the individual day-to-day are asked to put themselves in the place of the person with disabilities and think about the questions above, much can be learned. When there are involved family members, their participation in this process is invaluable.

Our first response in encountering a difficult behavior should not be to ask "how can we apply technology to reduce this behavior?" Rather initial responses should focus on meaningful, collaborative attempts to determine the nature of the distress the person may be communicating through his/her behavior and practical changes to the nature and quality of the person's life.

Not long ago I visited a small group home and talked with Roger and his staff about the behavior program that was in place for him. Staff explained to me that Roger's behavior problem was that he asked questions repeatedly. His behavior program required that he sit in the staff office alone for twenty minutes if he asked the same question more than once. "For example," one staff person told me, "he'll walk in from the day program and he'll say, 'we're going to watch the game tonight, right?' I'll tell him yes. Ten minutes later, he'll say, 'we're going to watch that game tonight, aren't we?' I'll tell him yes again. The third time, he goes into the office for twenty minutes." Roger understood the mechanics of his behavior program but seemed confused by its necessity. "Why is it so bad to ask questions?" he pondered, "a lot of times they tell me to do something over and over again."

I asked the staff member if he had any thoughts about why Roger might ask questions repeatedly. At first he said that he didn't know. Since he knew Roger reasonably well, I asked him to try to come up with some likely theories. He first suggested that Roger was doing it for attention, but with further discussion, he came up with several other good possibilities. One possibility was that in the past there may not have been follow-through when promises were made so Roger was, in essence, re-confirming the commitment. His second thought was that maybe this was Roger's only way to initiate social contacts. Finally, he suggested that maybe Roger actually found it hard to hold the idea in his mind; that as time went on he really did not remember what had been promised.

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It May Be Non-Aversive. But Is It Non-Coercive?: The Ethics of Behavior Change

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How different services would look if we were as motivated toward being humane as we are toward imposing controls.

I commended the staff person for coming up with several excellent possibilities and asked the staff person what he thought would happen, if, the second time the question was asked, he sat down with Roger and said something like: "Gee, I can tell you're worried about this. I don't want you to worry, because I've given you my word. I want to give you something that might help. I am writing my promise to watch the game with you on this piece of paper. I'm going to sign my name. I don't sign my name unless I'm really going to keep a promise. If you get worried again, maybe you could look at this paper and it will help to remind you that I've given my word. If you're still worried after you look at the paper, you can come ask me again. I don't want you to be worried." How different services would look if we were as motivated toward being humane as we are toward imposing controls.

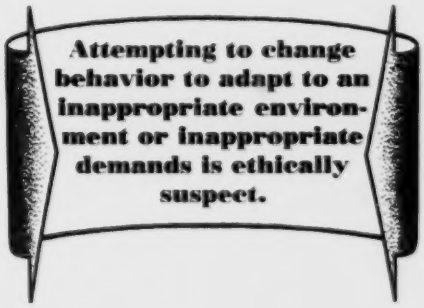
After this conversation I gave some more thought to the staff person's initial hypothesis - that Roger was asking questions for attention. It's an observation that is often said with a level if disdain, "it's just attention-seeking behavior." What if, rather than seeing the quest for attention as a shortcoming, we were struck by how unfortunate it is that someone would need to act in remarkable ways to be noticed and we responded in loving concern?

Joan loved music. Each day when she returned home from school she would sit quietly for awhile listening to her favorite tapes. Her parents met with a psychologist to design a behavior program for Joan's behavior of destroying property. He started by asking her parents to list those things Joan found reinforcing. Music was at the top of the list. It was decided that her parents would hold Joan's cassettes. When Joan did not destroy anything all day she would be offered her choice of a cassette to listen to for a half-hour before bed. Joan's psychologist was shocked when his program was criticized - "but it's all based on positive reinforcement!" he insisted.

A person with a developmental disability once said, "I've got it figured out. You better not tell them what you like or they'll make you earn it and you better not tell them what you don't like or they'll use it against you"(Henning, 1991, lecture). Forcing adults to earn privileges that are (or should be) available to them already, or that are available to others, raises serious ethical considerations. Programs that rely heavily on positive reinforcement that is not directly related to the function of that person's behavior are contrived and intrusive. It is not necessary to bribe people to do things they find meaningful or pleasurable. When we are tempted to implement some complex system of positive reinforcement, it is probably a good time to step back and look at the big picture - to ask ourselves if there aren't meaningful changes that could be made in this person's life. The message we should be attempting to communicate should not be "I'm in control and you're not" but, rather, that the person's preferences, goals and feelings are worthy and deserve to be heard.

People with seriously difficult behaviors act not out of choice but because some need is unmet for them. Herb Lovett said, "My experience has been that extreme behavior often comes from not feeling listened to. Just as repressive organizational or political systems lead to aggression and revolution, the most profoundly disturbing behavior is often found in ... unresponsive service systems." (p.6).

Laura was in a regular fourth grade classroom but, because of her disabilities, her teacher didn't include her in many of the learning activities in which the other children participated. The teacher had selected a few activities for Laura that she felt were better suited to Laura's abilities. These included sorting pegs by color, putting together a puzzle, and matching objects to pictures on a grid. Laura showed curiosity about the activities of the other children. Their activities were generally of a more active and participatory nature. Laura would often wander around the classroom disrupting the work of the other students. When she was redirected back to her seat and her activities, Laura would often become upset, throwing her materials on the floor and occasionally even pushing and hitting the teacher.


Attempting to change behavior to adapt to an inappropriate environment or inappropriate demands is ethically suspect.

Laura's teacher enlisted the help of the school's behavior specialist to develop a program to encourage Laura to stay in her seat, attend to her work, and to reduce Laura's aggressive behavior. She told the behavior specialist that Laura was noncompliant. The behavior specialist was happy to begin designing a careful system of reinforcement to assist

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The Center on Human Policy, through its National Resource Center on Supported Living and Choice and its subcontracts with the University of Minnesota's Research and Training Center on Community Living and Responsive Systems Associates, distributes a variety of reports and resources on the inclusion of people with severe disabilities into community life. The project would like to make these reports available to you at cost. Due to space limitations this is a partial listing of the Center's newest publications; a complete list is available upon request.

ALTERNATIVE DAY ACTIVITIES

It's All Business: A Site Visit Report on Working Order, Sharpsburg, Pennsylvania (1998) by Marjorie F. Olney and Perri Harris describes an organization in Pennsylvania designed to assist people with and without disabilities to develop business ventures. (18 pages) $2.50

"This is Still a Work in Progress": Common Ground, Littleton, New Hampshire (1998) by Mair Hall and Pam Walker describes a program that closed its workshops and supports all people in integrated daytime activities. (25 pages) $2.70

COMMUNITY SUPPORTS/ INCLUSION

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Information Package on Disability Studies (1998) by Perri Harris and Lori Lewin includes information on recent books, academic programs, and web sites about disability studies. Also included are reprints of two articles about disability studies, one which includes an extensive bibliography, and the other an

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New Resources and Reports on Community Inclusion

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article and bibliography about developmental disabilities and disability studies. (106 pages) $5.40

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Resource Packet on Disability, Spirituality, and Healing (1999) by the Rev. Nancy Lane presents articles, an annotated bibliography, a course syllabus, and handouts on disability and spirituality. Much of the emphasis in this package is on the spiritual healing of wounds created within individuals by attitudes toward and discrimination against people with disabilities. (181 pages) $9.35

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Positive Behavioral Supports or "If I had known then what I know now..."

BY CLARA BERG

If I had known then what I know now, what would have been different? Who knows! Do I want to complain about our journey? Probably not!

We have come a long way as a family, as individuals and as mentors of good behaviors, not only with our son, who is deafblind, but with our other two children as well.

Kenny's life got off to a rocky start. He was born prematurely and was hospitalized for eight months. The doctors cautioned us not to expect him to make it to his second birthday. After Kenny finally came home from the hospital, we invested all of our efforts into maintaining his health and well-being, hoping that he might make it through that second year.

Fortunately, the doctors' predictions were wrong. He made it to birthday number two and beyond. In fact, we recently celebrated his 19th birthday!

When did Kenny start displaying challenging behaviors? I would have to say since birth. He was born a fighter and constantly fought to prove that he could make it and get his way. He started displaying self-injurious behaviors as soon as he developed some muscle tone in his tiny arms, at age two. He would bring his little hands to hit his head, or slap his face. As he grew stronger, the hit or slap was followed by a hit with his knuckles on the head or body. Then, since this motion apparently did not satisfy his need for self-stimulation, he learned to hit his head against sharp edges or hard surfaces. At times, he would strike himself so hard, we could hear them even if we were in a different room.

We came to the realization that we couldn't apply standard procedures because they didn't work. We needed to find out what in the environment triggered Kenny's behaviors, and what was Kenny trying to communicate to us through his behaviors. ...We were convinced that we were doing the "right thing" by following standard procedures on an individual basis.

Surprisingly, he never injured or bruised himself. As a matter of fact, we suspected that he developed a "built-in helmet" on his scalp. We used to wonder if all children with deafblindness tried to hurt themselves. Did they get some type of visual stimulation when they hit their heads?

We participated in various workshops to learn more about self-abusive behaviors. We asked many questions and received many different answers from professionals in the field.

As the years went by and Kenny grew stronger and bigger, his behaviors became more harmful. Communication became the main concern. We did not know much about teaching a boy who was deafblind to communicate his needs and wants with his hands. We had to learn new communication systems at the same time that we were teaching them to him. We give a lot of credit to the schools that worked with us and with Kenny. Many different methods of communication were introduced with the hope that if he could communicate his needs, his self-abusive behaviors would diminish or cease.

We tried to using our voices, FM units, American Sign Language (ASL), object cues, calendar boxes, various smells and textures. The hitting continued. Even a helmet and medication were unsuccessful in stopping the self-abusive behaviors.

When Kenny was 10 years old, I attended a workshop that helped me to comprehend the seriousness of these behaviors. I became very motivated to find an immediate solution before the behaviors were becoming worse. I began to get the idea that some students, Kenny being one of them, needed a more systematic method of planning on his daily activities. I began to learn about positive behavior support planning. The more I read and learned about it, the more eager we became to put it into practice.

Allow me to tell you in my own words about the components of our behavioral support plan.

Functional analysis:

In the school and at home, we started keeping data of when the behaviors occurred, how often they occurred and what triggered them. We assessed Kenny and his environment to enhance the effectiveness of instruction. These detailed assessments were performed using the Motivation Assessment Scale (MAS). We collected scatter plot data in school and at home, concentrating on one specific behavior at a time. During this period of time we would get together with the professionals and interpret all these data forms. We could not have done it without them, and they could not have done it without us.

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Positive Behavioral Supports or If I had known then what I know now

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Short-term prevention strategies:
The functional analysis helped us predict not only when behaviors would occur, but when Kenny was happy, what made him happy, and when he was busy, what kept him busy and not engaged in self-abusive behaviors.

Together with the school we began to identify Kenny's preferred activities and we began using simple methods to prevent Kenny from hitting. We used the preferred activities to teach him new skills.

Kenny likes to be outdoors; he was able to learn how to walk with his cane more independently. Kenny enjoys loud noices and motion; the school assigned him the job of collecting recycling cans and compressing them.

Kenny is happy in places with a variety of different textures and smells. At the present time, he spends weekend mornings working as a volunteer at a farm.

Instructional and environmental adaptations:
Methods of instructions were changed and adapted specifically for Kenny. He needed to learn when to ask for a "break" during an activity. We needed to learn to "adjust" our teaching pace to fit his learning style. Kenny got to spend more time with the staff and students that he preferred to be with.

Teaching alternative, adaptive behaviors:
We had to teach Kenny how to substitute communication for challenging behaviors, and we had to learn how to listen to and honor Kenny's communication. We learned that when Kenny was happy and relaxed it was easier for us to teach him and for him to learn. So we created pleasant situations and utilized elements that we learned through the functional analysis that would be effective to teach him many skills and different ways of communicating.

This process helped all of us to get to know Kenny better and to be able to identify what actions, people, situations and places he liked or disliked. We decided to work around those issues specifically.

The functional analysis and Personal Future Planning (PFP) were done at the same time that we began planning for Kenny's future. In a short period we learned more about Kenny and got to know him better than we had in years. When he was a little boy, we had discussed IEPs and schedules and routines that would benefit Kenny's education and well being. We were convinced that we were doing the "right thing" by following standard procedures on an individual basis.

We came to the realization that we couldn't apply standard procedures because they didn't work. We needed to find out what in the environment triggered Kenny's behaviors, and what was Kenny trying to communicate to us through his behaviors. If he would not cooperate starting an activity, we wouldn't tell him "it's time to..." rather "It's okay if you don't want to start now. Let's do something else that you like and then we'll come back again."

We know kids behave differently at home with their families than they do with their teachers at school. Each family has different dynamics and philosophies about functional, social and moral issues, as well as their own priorities and expectations with their children.

We have learned that we have to consider each member as a very unique individual. We believe that we succeeded in arresting Kenny's challenging behaviors, and the prize of our success has to be shared with the professionals that supported our efforts.

We worked in close partnership with the professionals, and the points that we would like to share with you are:

Positive outlook - We know our son/daughter "can do it," we trust them, we want to maximize his/her potential. We want to work with professionals who share our vision.
Effective communication - We express ourselves with accurate information and details without getting sidetracked by other issues that are irrelevant to the situation.
Perseverance - Behaviors do not change overnight. We tried many different approaches until we found one that we felt comfortable with. We applied it repeatedly until it worked. It took years!
Sense of humor - It's easier to engage in a challenging project if we can share a smile with other people. Let others know we enjoy their company and we want them around us. We can find humor in many aspect of our lives.
Instinct -Trust your instinct in any aspect related to your family. We know our families best!!

I know, I know. These five points form the word "Pepsi." This was not intentional. Now that I come to think about it, parents and professionals should celebrate their partnerships with the energy that a "Pepsi" brings, and enjoy the flavor of knowing that they have the unique chemestry that supports their common goals.

Clara Berg was born in Uruguay and has lived in the United States for 22 years. She and her husband, Jake, have three children, Sheldon 20, Kenny 19 and Karen 18. Clara is the Family Specialist at the New York State Technical Assistance Project, and has been active with the New York Parent Network and the National Family Association for Deaf-Blind.

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It May Be Non-Aversive. But Is It Non-Coercive?: The Ethics of Behavior Change

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Laura to achieve these behavioral goals. The ethical questions are clear. Simply because the technology exists to train Laura to be compliant in an inappropriate environment doesn't make it ethically acceptable. An astute teacher or behavior specialist would recognize Laura's behavior as one of the most objective critiques of service quality that they are ever likely to receive. Attempting to change behavior to adapt to an inappropriate environment or inappropriate demands is ethically suspect.

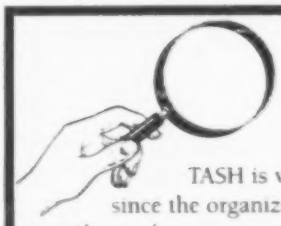
What if we eliminated the term "noncompliant" from our vocabulary? The word "noncompliant" doesn't appear in the dictionary because it is not a term used outside the disability/health care field. We stand up for ourselves. We are assertive and enterprising. Our children are spunky, and strong-minded. We do not buy self-help books to learn to be more compliant or encourage our children to master the skills of compliance. Only the people with disabilities with whom we work are labeled "noncompliant" when they attempt to forge their own directions. When people do not act in a cooperative way our first question should be whether we are asking them to do something that is meaningful to them. Many of us avoid doing things that we do not find personally fulfilling (think back to the last meeting you missed) -- we would rightfully resent a coercive attempt to force us to take part in meaningless activity. The best way to teach cooperation is to model it rather than to apply coercive interventions.

Whether efforts at behavior change are positive or not depend almost as much on the spirit in which they are offered as on the methods themselves. Rather than seeking ways to control people further we should be seeking ways to understand them and communicate to them that we are trying to help them act on their wishes, needs and desires.

When people feel valued and included they are much more likely to behave in ways that do not challenge systems or the people around them. It is not enough to design behavior programs that are non-aversive -- defining an approach by what it is not does little to describe what it is. As family members, advocates, teachers and others who work in the disability field, we have a responsibility to people with disabilities to ensure that any interaction in the name of "treatment or programming" is accomplished in a manner that supports that person to be spirited, self-directed and fulfilled.

Nancy Weiss is the Executive Director of TASH.

[1] Skinner, B.F. (1971). Beyond freedom and dignity. New York: Alfred A. Knopf, Inc. p. 150.
[2] Lovett, H. (1996). Learning to Listen: Positive approaches and people with difficult behavior. Baltimore: Paul H. Brookes Pub. Co., p. 6.



We're looking for YOU!

TASH is working to identify a list of people who have been members since the organization's inception in 1975. If you are one of these loyal members, please contact Nancy Weiss by phone (410-828-8274, ext. 101), e-mail <nweiss@tash.org>, fax (410-828-6706) or mail (see back cover for TASH's address).

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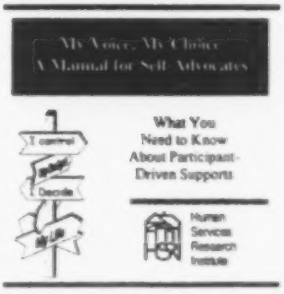
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What Restraints Teach

BY PAT AMOS

Nationwide attention is finally being paid to restraint-related injuries and deaths among people with disabilities. Predictably, however, efforts at comprehensive reform are devolving into discussions about ways to increase the safety of restraints via more regulations, trainings, documentation, and review committees. In the escalating quest for behavior control, an army of technicians is always ready to answer "How?" Somewhere behind them, there will usually be an overworked clean-up crew asking "Why?"

Why are restraints, from basket holds to "take downs" on the floor, used on children and adults with disabilities in the first place? A common reply is that people need to be restrained if they pose a danger to themselves or others. Now if I am out walking with friends, and I step into the street without looking just as a car comes speeding past, I hope that someone will grab me and pull me out of harm's way. Next time we come to a busy street, my friends might want to keep a closer eye on me, or remind me to look both ways. They might even take me for more walks in the park or the open countryside. But I would be very chagrined if my friends decided that my "crossing the street behavior" was "likely to escalate into a dangerous situation" and wrestled me to the ground every time I headed toward a curb. A line would be crossed when an emergency response (while my friends figured out what to do) became a standard procedure (what my friends habitually would do). Of course, at this point I might conclude that it was time to find some new friends.

Many people with disabilities need, but cannot find, new friends who will stop assaulting them. These two realities define the special danger and injustice inherent in the use of restraints on people with disabilities: they are used repeatedly as standard procedure, and the people on whom they are used have no right or power to end these abusive relationships.

Some behavior trainers insist that restraints have therapeutic value. This value is calculated on the dubious assumption that people cannot participate in school or community unless their bodies are in a certain position. By forcing a person's body to do something it would not otherwise be doing, practitioners of restraint apparently hope that the person will learn to conform to the desired activity in the future. Even were it possible to believe that some sort of gross and heavy-handed "patterning" is taking place, however, the enforced activity seldom relates to the avowed goal. Children who get out of their chair have been restrained in the chair, grabbed in a basket hold, flattened on the floor, or dragged to a locked room. A person who hits his head may undergo the same treatment. What is there about being held in a chair, grabbed in a basket hold, flattened on the floor, or forced into a locked room, which can teach such diverse lessons as how to sit in a chair, when not to get out of a chair, not to slap one's head, and what to do when frustration or headache prompts you to slap?

Restraining a person to achieve a nicely-posed "look" of the activity the teacher or staff person desires makes about as much sense as trying to train the next Sammy Sosa by duct-taping him to a bat.

Of course, the ultimate way of keeping such behaviors under control has been discovered by many staffers who have restrained clients until all behaviors ceased, permanently. Having successfully completed their behavior plans, these clients were released from their programs despite their inability to appreciate such an enduring outcome.

Finding reasons and means for conforming your body to a piece of furniture, like finding solutions to the problem that is causing you to hit your head, is a process that requires time, options, and individual choices. It also requires supports and accommodations, meaning that aspects of the environment, not just of the person, must be adjusted. Restraining a person to achieve a nicely-posed "look" of the activity the teacher or staff person desires makes about as much sense as trying to train the next Sammy Sosa by duct-taping him to a bat. Most coaches prefer to see a trainee work out his own unique way of connecting muscles, nerves, and reflexes with the challenges of bat and ball, and even believe that love and understanding of the game are vital to success.

If restraints are unlikely to teach better ways to problem-solve with our bodies, could they perhaps teach something useful about social expectations and how to relate to others? Some behaviorists argue for restraints as an impressive means of extinguishing anti-social and promoting pro-social behavior. While their plans pay homage to the role of the environment in producing behavior, these same behaviorists seem blissfully oblivious to the crucial piece of the environment that includes themselves. They take pride in "carrying out the intervention" with no show of emotion or involvement, believing their role is neutral and their activity means only what the behavior plan says it means.

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What Retraints Teach

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Staffers come to believe they can tackle a noncompliant client to the floor, and the client will feel nothing but a sharp desire for self-improvement.

"When I use a word," says a proto-Skinnerian Humpty Dumpty in Lewis Carroll's *Through the Looking Glass*, "it means just what I choose it to mean — neither more nor less....The question is which is to be master, that's all." Those who choose restraints as teaching tools likewise assume they can master the meaning their tools construct, as if they were writing commands to feed into a computer. But the human brain is not like a computer. Human meaning cannot be pre-packaged or contained; it cascades out of any human contact, creating impacts far downstream. The actions of a person with power forcibly restraining a person without, and the responses of bystanders and the larger community, create meaning in emphatic and memorable ways. After many conversations with people who have been subjected to restraints, and with their families, I can offer the following list of lessons that restraints teach:

1. The world is a very dangerous place. I could be killed at any moment.

2. My parents, and those others who claim responsibility for me, cannot be trusted to protect me.

3. My body is not my own. I have no right to personal space.

4. Might makes right.

5. I am a bad person.

These lessons have two things in common: they are about the disruption, even the futility, of human relationship, and their consequences flow far into the future. Generalized fear inhibits the ability to explore and learn. Distrust of others interferes with emotional growth. Being taught to accept restraint and give up rights over one's body makes many people with disabilities into ideal targets of sexual abuse — victims who are unlikely to attempt to communicate the abuse, since they have also learned that those who care about them cannot protect them. Post-traumatic stress disorder (PTSD) frequently develops in situations of ongoing danger and fear, when the usual options of "fight or flight" are cut off. Those who do attempt to fight against restraint increase their risk of injury or death. Others, having observed that the world is ruled by brute force, will wait until they grow larger or those in control drop their guard before demonstrating what they have been taught. Many victims of restraint conclude that they must deserve pain and humiliation, and descend into despair.

When we resort to restraints, we damage deep roots of human relationship which have been growing from the start of every person's life. I once knew a four-year old child whose speech, although mostly echolalic, was punctuated by several pairs of opposites which he used with great emphasis. His favorite pair was "broken" and "not broken." While he had ample opportunity to pronounce toys with dead batteries "broken", I became fascinated with the other ways he applied this term. A locked door to a room to which he had always been allowed access, a parent who loses track of time and starts dinner late, or a canceled visit from his Grandma, all were "broken." It slowly occurred to me that what he became most indignant about was the breakage of relationships and his expectations of them. He was, in fact, putting forth a deeply moral point of view which said that decisions affecting his participation and power in the world should not be arbitrary — which is to say, made or unmade without him. He had certain relationships of trust, access, and reciprocity which were of central importance to him, and these were not to be violated. His young age, and the fact that he carried a disability label, did not make his expectations any less urgent.

Much later, this same child would pass through several difficult years during which his behavior slipped out of his control in frightening ways. Some professionals advised that he be removed from home and forcible means applied, if necessary, to stop these episodes. Confinement in the local psychiatric facility, it was suggested, would "teach him something" about the need for self-control. Though tempted, his family refused this assistance on the grounds that, in resorting to force, their relationship with this teenager could indeed be "broken". When he would rage and test their commitment, they assured him that he was safe and secure. Slowly their son stopped panicking and, as his confidence returned, he was able to help his family help him. The storm passed, and nothing that mattered was broken. Five years later, full of pride and curiosity, that young man went off to college. He is currently majoring in Communication.

Restraint, which shuts down communication, can only teach negatives. It is a "quick and easy fix" in the same sense as dumping your leftover pesticides in the creek: the clean-up crew downstream will have to cope with the ruined ecology for years to come. Only through honoring the complexities of communication and relationships do we have any chance of moving beyond the mechanics of regulations and safety committees to the creation of organic, flexible, evolving adaptations to life's challenges.

Pat Amos is with the Autism National Committee.

Autism National Committee
Policy on Restraints

In the wake of the *Hartford Courant's* groundbreaking series last year entitled Deadly Restraint, states across the country are designing legislation and regulations to prevent the inappropriate use of restraint. Our friends at the Autism National Committee have adopted the most strongly worded statement I've seen:

The Autism National Committee condemns the widespread and excessive use of restraints in restricting the civil and human rights of people with disabilities, and affirms that the use of restraints should be considered a failure of treatment.

People who have survived forceful restraint have reported they feared they would die in restraint, and some have died. A number of tragic cases of restraint-related deaths of children and adults have recently made the national news. Estimates of deaths occurring during or shortly after restraint currently range from 50 to 150 annually. The actual magnitude of such deaths is poorly tracked and subject to under reporting. A federal Department of Health and Human Services spokesperson has agreed that these deaths are under reported.

Many have reported that they now live with fear and flashbacks that involve a sudden, involuntary re-living of this emotional and physically traumatic experience. Post-traumatic stress disorder is increasingly being diagnosed among persons who have been subjected to the systematic use of restraints. In our experiences as professionals, parents, and individuals with autism, we have witnessed too many times the horror and injury done to our citizens with autism. We are weary of seeing our people become victims.

It is clear that: individuals' sometimes desperate efforts to communicate are ignored when staff force compliance for oftentimes trivial reasons; the cumulative effects of repeated restraint can lead to diminished self-image and negative attitudes; when restraint is used, struggle is provoked and this natural response increases the danger of physical injury.

Although any one of us, disabled or not, may at some point in our lives need to be restrained on an emergency basis, that should only occur when there is a substantial threat of injury to self and others. Behavioral restraints are neither treatment nor education. They are merely procedures or methods that restrict freedom of choice and adversely affect the human development of people with disabilities, and as such we totally condemn their use.

We call on national and state agencies to investigate the widespread mistreatment of people with disabilities through the use of restraints. We call on Congress and state legislatures to pass legislation to protect people with disabilities by: limiting the use of restraints on children and adults with disabilities to one-time emergency situations involving serious threat of injury to the person with disabilities or to others; requiring immediate reporting of these incidents; requiring thorough investigations of the circumstances that lead to the incident; and requiring the development of supports and accommodations to prevent future incidents.

adopted 9/3/99

TASH has modified our resolution on Positive Behavioral Supports to clarify our position. We welcome your comments.

TASH RESOLUTION ON POSITIVE SUPPORTS

WHEREAS, TASH's resources, expertise and advocacy are dedicated to the development, implementation, evaluation, and dissemination of positive educational and behavioral support practices that are appropriate for use in typical community settings and are consistent with the commitment to a high quality of life and personal satisfaction with life for individuals with severe disabilities.

WHEREAS, Educational and other habilitative services must employ instructional and support strategies which are consistent with the right of each individual with severe disabilities to effective support without compromising their equally important right to freedom from harm (including access to strategies that provide for physical safety).

WHEREAS, Current research and practice have demonstrated the practical efficacy and benefits of functional behavioral assessment and positive interventions for helping to resolve the challenges of problem behavior affecting people with severe disabilities.
WHEREAS, Individuals with severe disabilities have the right to equal access to medication, emergency, and safety procedures available to individuals not labeled with a disability, according to legal, regulatory, personal, family, and community standards.

WHEREAS TASH, calls for the cessation of the use of any educational, psychological, or behavioral intervention that exhibits some or all of the following characteristics:

(1) dehumanization through the use of procedures that are normally unacceptable in community environments for persons who are not labeled with a disability; (2) obvious signs of physical pain experienced by the individual; (3) physical injury and potential or actual side effects such as tissue damage, physical illness, and/or severe physical or emotional stress; (4) effects which would require the involvement of medical personnel, and/or other health care authorities; (5) ambivalence and discomfort by the individual, family, staff, and/or caregivers regarding the use of interventions or their own involvement in such interventions; (6) signs of community or peer repulsion or stress from witnessing procedures that are widely divergent from their standard of acceptable practice; (7) the use of physical restraint for any purpose other than crisis intervention to protect individuals from imminent harm; and/or (8) the use of sedative drugs ("chemical abuse") for the sole purpose of behavior management.

IT IS RESOLVED, That all persons with severe disabilities shall have access to approaches that enable them to positively affect their lives in ways that are meaningful to them. Therefore, educational and other support services applied in situations involving problem behavior must: (1) be developed in collaboration with the individual in a respectful and culturally sensitive manner that facilitates self-determination; (2) be based on a functional behavioral assessment of the internal and external variables that may be affecting the person's behavior; and (3) use the findings of the aforementioned analysis to develop constructive and comprehensive approaches- including medical, educational, communicative, and environmental interventions- to assist the individual to address the circumstances that adversely affect his or her behavior. Further, supports should be provided in a manner that maximizes access to, and participation in, the full range of typical home, school, and community settings, in order to maximize the individual's personal well being.

Originally adopted October 1981
Revised November 1986
Revised February 1999

Positive Behavioral Support: Making It Happen

Continued from page 18

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Authors Carole R. Gothelf and Jennifer Teich are with the Jewish Guild for the Blind in New York and Jerry G. Petroff is with Temple University in Philadelphia.

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Priscilla Newton, *Editor*

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

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VOLUME 25/26 ISSUE NUMBER 12/1 DECEMBER 1999/JANUARY 2000

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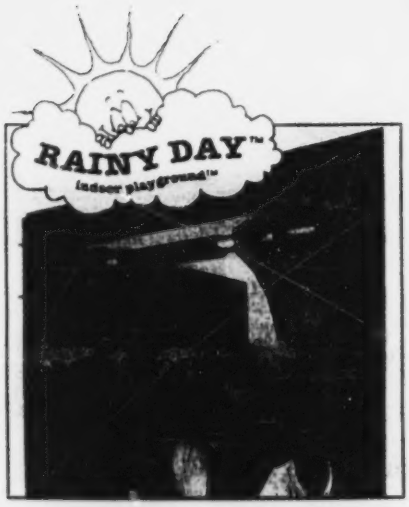

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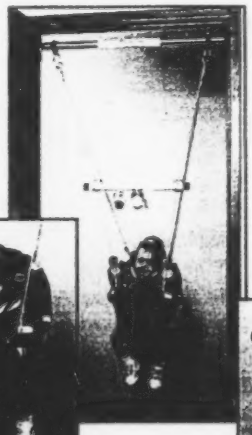

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

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Stretching the boundaries of what is possible;

Building communities in which no one is segregated and everyone belongs;

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Advocating for opportunities and rights;

Eradicating injustices and inequities;

Supporting research and disseminating knowledge and information;

Promoting inclusive education;

Supporting progressive legislation and litigation; and,

Promoting excellence in services.

From the Executive Director
BY NANCY WEISS

At the dawn of this new millennium and in honor of TASH's twenty-fifth anniversary year, we thought it fitting to visit with some people who were central to TASH's history. In this issue we hear from some of the founders and past presidents of TASH as they reflect on TASH's roots and future. When I ask people what they most want to know about TASH, they first want to know what the acronym "TASH" stands for (if you are still wondering about this yourself, see the boxed section entitled "What's In A Name?" at the end of page 7). The second thing people are most curious about is TASH's history – Who started TASH? How and why? When and why did it move from Seattle? A few years ago, I wrote the following in hopes of answering some of these questions:

Like many of you, for years I've heard reference made to the mysterious, great birthing that took place in a hotel room in Kansas City. But I've always had questions ... What led to this meeting? Who was there? Whose idea was it to start a new organization - and why? For all of you who have lain awake at night wondering about the same things, here's the story, straight from several of the horse's mouths!

In November, 1974, the Research and Demonstration Program funded by the Division of Innovation and Development of the Bureau on Education of the Handicapped (now called the Office of Special Education and Rehabilitative Services) held its first annual seminar. Ed Sontag was a bureau chief for the Bureau on Education of the Handicapped. He came to this first seminar with an idea for a new organization germinating. He had already spoken with Norris Haring about this idea and they both felt that a new national organization that focused on the educational and other needs of children with more severe disabilities was needed. Sontag and Haring felt that a new organization would be the best way to gain immediate attention to the needs of these children.

Continued on page 7

Whom Do I Contact??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
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TASH LEADER LOU BROWN — Setting the Pace

BY DONNA GILLES

This issue of the TASH Newsletter would not be complete without words from Lou Brown about the history of where TASH came from, and the future of where TASH is going. Lou was not available for us to interview for this article, as he is busy preparing testimony in the case ARC Connecticut v. State of Connecticut. So, I offer a few words about him from my perspective. Lou, forgive me! – Donna Gilles

One of my worst fears about aging as a professional is that more recent participants in disability work will not know the history of the inclusion movement, and the people who helped get us where we are today. One of the people everyone in TASH should know about is Lou Brown. Not only was he a founder of TASH and one of its first presidents, he helped recruit many of the current leaders to TASH. Also, as a professor at the University of Wisconsin, Lou has graduated some of the finest professionals in the field, and no college student in the field of supporting people with disabilities completes his/her studies without hearing his name a few hundred times.

When I first met him 24 years ago, Lou Brown was not yet a household name, but he was on the verge of becoming a legend. He actually came to the school where I was teaching in Maryland. It was a segregated facility for students with disabilities. PL 94-142 had just been passed, and we were the first school in the county (maybe even the state) that enrolled students with severe disabilities. He came to demonstrate instructional strategies that he, his colleagues, and his students had found to be successful in facilitating acquisition of skills by students who traditionally had not been exposed to educational activities. I remember sorting blocks and bears, but remember more his conviction

that students who were never viewed as having any strengths could learn to sort, make sets, discriminate.

A short time later, because of Lou and his colleagues, blocks and bears became taboo because of their irrelevance to real life. Of course, what goes around comes around – now that some general education kindergarten classes use blocks and bears as instructional materials, five-year olds are once again allowed to use them! I remember the respect with which he spoke about the people living in institutional settings. I remember Eugene (does anyone else?). Watching the tape about Eugene was what cemented my choice of careers.

I joined TASH in 1978. The question I most often heard was, "Has anyone seen a recent article that does not have Lou Brown's name on it?" He appeared to be everywhere, and the impact of his message was powerful, life-changing, and has transformed systems and helped shape the world as it is today. Years ago, I was fortunate enough to catch a couple of his early conference presentations when he was on his "Ready or Not, Here We Come" roll, talking about community participation; and his "Where are Your Priorities?" offering, using the example of the "prom and the pimple."

Then came the evolution of inclusion. Early on, I was skeptical about the idea of having students with disabilities being educated in general education classrooms (of course, look where I was teaching!). I went to a session which I consider one of Lou's finest, although I don't remember when and where it was. He had the audience in hysterics one minute and silent the next. His wit entertained us for a few minutes and then with the accuracy of a surgeon with a newly sharpened scalpel, sliced through our dense skulls to the area of the brain that held our consciences, forcing us to ask ourselves, "What could we have been thinking?" I, for one, feel a lot better now, his medicine having worked.

For many years, he has been TASH's Connections Ambassador. When you see him at the annual conference every year, he is always pulling someone over to someone else making sure that important connections are made between people who have common interests or who live in the same area. This is one of the most important things that anyone can do for TASH. Our membership thrives on connections. Two years ago, a friend of mine attended her first TASH conference and she said that if she got nothing else out of the conference, attending would be worth it if she could meet Lou Brown. She said it with the same excitement that people had 20 years earlier when they heard him speak or met him for the first time.

I'm sure the people who know him well are about to strangle me for attempting to swell his head. I know it sounds like he is larger than life (and he is pretty tall), but he's also a down-to-earth, caring man. We're fortunate to have had Lou Brown to help formulate the inclusion, community participation, community employment agenda that is so much a central part of TASH. Thanks, Lou.

Donna Gilles is a member of the Executive Board of TASH.

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TASH's Influence and Leadership Grows Over the Years

BY DR. BUD FREDERICKS

When TASH (originally the American Association for the Education of the Severely/Profoundly Handicapped - AAESPH) was organized in the mid-1970s, I was a research professor at Teaching Research. I was developing model programs in early intervention and elementary school for children with moderate and significant disabilities. Although I was not involved with the initial establishment of TASH, I was kept well abreast of the association's work through my colleague, Victor Baldwin, who was a member of the first TASH Board of Directors.

I served on the TASH Board and was the president for three years following the tenure of Wayne Sailor. All total, I was a member of the TASH Board for nine years. I am now retired, but am active locally. I still advocate for services for individuals with disabilities. However, I also have become involved in juvenile justice issues, having orchestrated the writing of the Juvenile Crime Prevention Plan for Benton County in Oregon. I serve as the chair of the Juvenile Justice Task Force and have completed studies on the child abuse system in the county and evaluated the county detention center. I am also a federal monitor for the California Youth Authority.

The Scope of TASH's Influence and Leadership

There were over 2000 children, youth, and adults in the state institution in Oregon in the mid-'70s. Classroom services were segregated, and there were a few segregated schools in Oregon. There were only sheltered workshops and I, my wife, and a few other advocates established a group home for persons with significant disabilities in Oregon. This was the second one in the state and ten people lived there.

TASH became the leader in the United States for advocating for the deinstitutionalization of large institutions, the dismantling of segregated schools and in the early stages, the integration of children with significant disabilities into public schools and classrooms. The term "inclusion" was not adopted until much later. TASH became involved in litigation throughout the country to achieve these goals and a select few of us were very active in testifying in these cases.

The influence of TASH overseas also became evident. TASH leaders were welcomed in Australia, New Zealand, and European countries and were invited to give workshops and lectures in all of these countries. I had the opportunity to testify in legal cases in Perth, Australia to assist a youth with significant disabilities to enter a regular educational program. I and my staff spent many months in Australia assisting the reform efforts in the educational system in institutions in Melbourne.

The Work of TASH Has Significantly Impacted the Lives of People with Disabilities

Institutions have been reduced in size and many have closed. Segregated schools have been closed. Children and youth are now included in public schools. Supported employment and supported living programs are now the programs of choice. All in all, children, youth, and adults with disabilities have become an integral part of the American culture. TASH has played an important role in the last quarter of a century in assisting the efforts toward integration and inclusion of people with disabilities in every aspect of life.

To name but a few of the accomplishments in which it can take pride, TASH has worked hard and diligently in the areas of deinstitutionalization, desegregation, and the design and implementation of non-aversive behavior programming. TASH has helped me to focus on advocacy issues and has helped me define my own philosophical position regarding inclusion and behavior programming.

A Unique Organization

TASH has been the leader in the areas ofdeinstitutionalization and positive behavior supports. Other professional organizations have followed TASH in these efforts.

Many states are struggling with state budgets. In such times, there is a tendency to cut funds from social programs and especially programs for people with disabilities. We see much evidence of this happening in public schools today. Consequently, there has been a gradual erosion of the quality of many of the programs that were once considered models of excellence.

It is important for TASH to continue to advocate for excellence and never allow schools, residential programs, and vocational programs to become mediocre. There is also a need for continued advocacy to increase the number of residential opportunities and community-based vocational programs for people with significant disabilities.

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From the Executive Director

Continued from page 3

Ed Sontag raised the issue of a new organization to the seminar participants. He proposed that a meeting be held to discuss the viability of this idea and after receiving favorable response, scheduled a special meeting to be held after the completion of all of the seminar-related presentations. The meeting was attended by fifty-five seminar participants. Sontag opened the meeting by presenting the purposes that he envisioned would be served by an organization that supported the delivery of quality services to children with severe or profound disabilities. After some informal discussion, the group selected Alice Hayden to serve as temporary Chairperson. She raised the following question: "Should an organization be formed to promote the professional preparation of personnel, to establish a system of information dissemination, to strengthen advocacy on behalf of students with severe disabilities and to perform political activities on behalf of these students?" There was widespread support for the establishment of such an organization. A lively discussion ensued that lasted until well after midnight. It was suggested that a smaller subcommittee be formed to continue the discussion, refine the organization's goals, suggest a name for the organization and name interim board members and officers.

So, that brings us to the smoke-filled room. As Norris Haring told me recently, "A lot has changed since that famous evening of November 14, 1974. Not only was the room smoke-filled, the favored menu choice was oversized Kansas City steak, and there were only six public schools in the country that provided service programs for students with severe disabilities." The subcommittee worked into the early morning hours. On November 15, 1974, the first official meeting of the newly formed **American Association for the Education of the Severely/Profoundly Handicapped (AAESPH)** took place. The pro tem officers and board members were introduced: **Norris Haring**, President, **Lou Brown**, Vice President, **Francis Anderson**, Secretary, and **Bob York**, Treasurer. Other Board members included **Diane Bricker, Marilyn Cohen, Laura Dennison, Marc Gold, Doug Guess, Wayne Sailor,** and **Richard Whelan.**

When Norris Haring returned to Seattle, he asked William Dussault to draw up the articles for incorporation as a non-profit organization in the State of Washington. The organization was incorporated on April 4, 1975. Bill Dussault remained TASH's attorney, contributing services pro bono, until our move East.

The first official meeting of the AAESPH took place November 12-14, 1975, again in Kansas City, Missouri. The newly confirmed board members of the AAESPH were introduced by **Doug Guess** as follows: **Norris Haring**, President; **Diane Bricker**, Vice President; **Verna Hart**, Secretary; **Bob York**, Treasurer; and **Alice Hayden**, Chairperson. Additional Board members were: **Vic Baldwin, Lou Brown, Tim Crowner, Marc Gold, Camille Peck, Wayne Sailor, Ellen Somerton, Jim Tawney, Dick Whelan and Wes Williams.**

From 1974 to 1975, the organization grew from the original thirty-two members to over 1200. Norris Haring and Ed Sontag recently wrote the following:

It was our vision in 1974 to create an organization that was unique and would make a difference in the lives of children with moderate, severe, and profound disabilities. We succeeded in establishing a professional community recognized for excellence in the education of these students. The principles under which this organization was established are as viable today as they were then.

Liz Lindley was TASH's first Executive Director and remained in that role until 1992. In January, 1993, George Flynn became the Executive Director. He served in that position for about a year.

In early 1994 the Board decided that it was time to move the central office of TASH from Seattle to a location closer to Washington D.C. For a number of years, beginning in the mid-eighties, TASH had a second office in Washington, D.C., that focused on issues concerning Governmental Affairs, ably run by Celane McWhorter, TASH's Director of Governmental Affairs. This office closed in 1993. The Board saw a need to consolidate operations in a location that allowed easy access to Washington D.C. I began my tenure as Executive Director in January, 1995. My first task was to move the organization from Seattle to Baltimore, the location selected by the Board as providing the best access to Washington D.C. while avoiding the stresses of being "inside the beltway." Unfortunately, none of the Seattle-based staff chose to relocate from Seattle to Baltimore. All of the staff who now support TASH started since TASH's move to Baltimore in March, 1995. Many of the current staff have been with TASH since just before or shortly after the move[1].

There have been many changes for the organization since its establishment. There have been several name changes, a broadening of focus to include very young children and adults with disabilities, a more global view of the disability community, enormous growth, and a move clear across the country. But the principles on which the organization was built and our fundamental purpose and vision remain unchanged. The need for an organization like TASH has not diminished since our inception 25 years ago. As we enter the new millennium, our commitment to social justice for all people with disabilities has never been stronger and our goals have never been more vital.

WHAT'S IN A NAME??

Many people want to know what the acronym TASH stands for. Here's a brief history of the organization's name. When TASH was started in 1974, it was called the American Association for the Education of the Severely/Profoundly Handicapped and went by the acronym AAESPH. In 1980 the name was changed to The Association for the Severely Handicapped, reflecting TASH's broader mission. The name was changed to The Association for Persons with Severe Handicaps in 1983, but the acronym TASH continued to be used. In 1995, the Board voted to maintain the acronym because it was so widely recognized but to stop using the full name of the organization because it no longer reflected current values and directions. Perhaps the best answer to the question, "What does TASH stand for?" is ... equity, diversity, social justice, and inclusion!

[1] *Many thanks to Norris Haring and Ed Sontag for their assistance in preparing this history.*

Remembrances of TASH Founding Member

NORRIS HARING

The First TASH Meeting

I was the founding president of the American Association for the Education of the Severely/Profoundly Handicapped (AAESPH). A few years later the name of the organization was changed to The Association for the Severely Handicapped (TASH). At the beginning of TASH's existence, I was the Director of the Experimental Education Unit at the University of Washington in Seattle.

At that time, people with severe disabilities were in residential institutions and received little, if any, services including education, therapies or rehabilitation and job training. People with disabilities were completely segregated from society.

The earliest TASH meeting began when a planning meeting was arranged by Ed Sontag and Paul Thompson to bring together the directors and other staff involved in the first of a series of demonstration projects located strategically throughout the country. These projects were designed to show that children with severe disabilities could be educated and ultimately live and work in their home communities.

The meeting was held in Kansas City. After the project presenters had completed their sessions, some 36-40 of the attendees gathered and after several hours of discussion, voted to initiate a non-profit association to benefit all persons with "severe handicaps." I was charged by the committee to develop the association's Articles of Incorporation and the By-Laws. Having no experience in the legal aspects of incorporation, I summoned the assistance of William Dussault. Dr. Alice Hayden and myself met with Bill and gave him our interpretation of the goals and objectives for the AAESPH and he drew up the papers for incorporation and filed our application with the State of Washington.

The following year, 1975, marked the first meeting of TASH (then AAESPH), held again in Kansas City. The first few meetings were like a large family gathering, totally dedicated to advancing education, research, professional preparation, dissemination and transdisciplinary services. (See the article by Ed Sontag and Norris Haring on the history of TASH, originally published in JASH (Spring 1996) and re-printed in this issue of the *Newsletter* beginning on page 9).

TASH's Work and Influence Are Far-Reaching

TASH was the single most important national association in influencing the provision of services of all kinds (pre-school, school-community inclusion, vocational training, publications and research). TASH's activism helped to generate a quantum leap of changes from segregated facilities to full inclusion in schools and communities.

From 1975 to the present, nearly 25 years, TASH has been a prime mover in bringing persons with severe disabilities from segregated facilities to fully inclusive environments throughout the nation and in a few countries outside of the U.S. TASH is an organization which is totally dedicated to the lives of persons with disabilities — dedicated to enhancing their development from birth through aging.

TASH's Achievements Through the Years

TASH should take pride in its achievements, including its leadership in:

- Assuring inclusive education for all students;
- Closing the most punitive of residential institutions and providing close monitoring of the institutions that remain;
- Increasing the regard, respect and the rights of all persons with disabilities in society;
- Contributing significantly to the legislation that led to IDEA and the ADA;
- Stimulating the development of university programs for the preparation of professionals in the disability field; and
- Stimulating research programs and peer reviewed journals such as JASH, the TASH *Newsletter* and JABA.

For me personally, TASH has played a major role in my career since its founding in 1975. The organization has guided my goals in the publication of research, teaching and theoretical formulations.

TASH is unique because of its unqualified dedication to all diversity, with particular emphasis on persons with disabilities. As members, we realize that the respect for the rights of persons with disabilities is their entitlement. Further, it is our responsibility as leaders to promote these entitlements for all persons who have been marginalized by society.

TASH's Leadership in the Field Continues

TASH's role as a leader in the disability rights movement is far from an end. We must follow the same basic philosophy and direction that has led to such significant changes in all aspects of life for persons with disabilities. We should strengthen our responsibility by providing leadership to other organizations that have now assumed various roles in improving the lives of people with disabilities.

The Professionalization of Teaching and Learning for Children With Severe Disabilities: The Creation of TASH

BY: ED SONTAG, UNIVERSITY OF WISCONSIN-STEVENS POINT • NORRIS G. HARING, UNIVERSITY OF WASHINGTON-SEATTLE

The following article appeared originally in the Spring 1996 issue of JASH.

The authors of this article often have reflected on the significant events surrounding the creation of the American Association for the Education of the Severely and Profoundly Handicapped (AAESPH), now known as The Association for Persons with Severe Handicaps (TASH). The history of TASH is about the history of the professionalization of the teaching of children with severe disabilities. (Note: To the extent possible, "people first" language is used throughout this article. However, at times, the recounting of historical events utilizing historical citations resulted in retaining the original language of the period.)

Such a history seemed especially timely considering the 20th anniversary of the first meeting of the AAESPH, which coincides with the 20th anniversary of the passage of the Education for All Handicapped Children Act (P.L. 94142). Although we have attempted to recall the events with a comfortable degree of accuracy, we do not claim that ours is the only legitimate voice for writing this history. We simply decided it was our time to do it.

The article is organized chronologically according to the events that are salient in our minds as both the source of and influence on our participation and involvement in the transformation of public education for children with severe disabilities. First, we acknowledge the significant events that established the historical context for the emergence of a subspecialty in special education for children with severe disabilities. Second, we situate the creation of AAESPH within the political context of the Pennsylvania Association of Retarded Children (PARC) consent decree and *Mills v. Board of Education* litigation. Finally, we expand this history of factual events with our own narrative stories based on our involvement in the movement to provide public education for all children with disabilities as (a) a federal official assigned to develop this new subspecialty (Ed Sontag) and (b) the first President of this new association (Norris Haring).

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It was our vision in 1974 to create an organization that was unique and would make a difference in the lives of children with moderate, severe, and profound disabilities. We succeeded in establishing a professional community recognized for excellence in the education of these students. The principles under which this organization was established are as viable today as they were then.

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Historical Context Preceding PARC

We begin with a review of the conditions and events surrounding the 1958 debate between Ignacy Goldberg and William Cruickshank concerning the responsibility of the schools for providing services to "the trainable" (Goldberg & Cruickshank, 1958). This debate marked an important trend in American education toward the public schools' acceptance of the responsibility for children with moderate retardation (IQ 35-50). Recognizing the potential of these children, who until this time were considered noneducable, was the beginning of a major shift toward including children. Acknowledging the right of all children and youth to educational services marked a significant increment on the continuum from segregation to full inclusion.

In the Goldberg and Cruickshank (1958) debate, Goldberg argued that the trainable child is the responsibility of the public schools. Even so, he imposed criteria stipulating that the child (a) be of school age, (b) be developing at a rate of one-third to one-half that of the child without disabilities, (c) have potential for self-care tasks and self-protection, (d) have potential for social adjustment in the home and community, and (e) have potential for economic usefulness. Meeting these performance requirements, then, the child had the right to be trained to the maximum of his or her ability. Further, according to Goldberg, the public schools had responsibility to design programs and provide appropriate educational services.

Cruickshank, on the other hand, argued that these children are not educable and, therefore, should not be the responsibility of the public schools. Further, Cruickshank cited Dewey's definition of education to strengthen his position against public education for these children. This definition requires that the student be able to generalize, solve problems, make judgments, conceptualize in abstract form, and utilize language concepts. Cruickshank argued that children with moderate retardation lack these abilities. Further, he argued that education essentially is for those who can return something tangible to society and assume a self-directed role in society. These goals were, accordingly, unattainable by those with severe or moderate retardation.

Cruickshank recommended as better alternatives that (a) these children be placed in residential institutions, (b) new

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types of residential schools be established, (c) those institutions already in existence be improved, and (d) community daycare centers be provided. These centers could provide the services needed and establish the association with the ultimate residential placements. It is illogical, Cruickshank concluded, to place the responsibility on the public schools to serve children who ultimately will not live in the community.

The tide toward educating children with moderate disabilities had already begun. In 1956, about 7,000 children who were labeled trainable were receiving services in the public schools. By fall of 1956, 29 states had passed legislation either mandating or providing reimbursement for the public schools to serve these children (Goldberg & Cruickshank, 1958).

Two years after the "great debate," John F. Kennedy was elected President of the United States. Influenced by a sister with mental retardation, he played a major role in advancing the cause of providing public school services for children with disabilities. In 1961, he commissioned a presidential panel on mental retardation, which made far-reaching recommendations regarding prevention, deinstitutionalization, rights, dignity, and care of individuals with mental retardation. He elevated federal programs for special education from a division to a bureau — the Bureau for Education of the Handicapped (BEH) with three major divisions: the Division for Assistance to States, the Division for Professional Preparation, and the Division for Innovation and Development.

In 1962, Congress passed legislation establishing 24 research centers throughout the nation, centers that would investigate causes of mental retardation and interventions for children with this disability. To apply the findings of the research centers, funding was granted to a large number of university-affiliated facilities that were to provide (a) management and educational demonstrations of appropriate interventions and (b) advanced settings for interdisciplinary professional preparation. Much of the applied research and development identified intervention strategies providing hard evidence that even children with the most profound disabilities could learn. Many of the centers conducted research demonstrating the successful application to persons with mental retardation of behavior principles (Haring, McCormick, & Haring, 1994).

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The PARC and the *Mills* litigation established the precedent for the necessity for public schools across the nation to provide educational services for children with severe and profound disabilities.

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The Contribution of Applied Behavior Analysis

It is instructive to acknowledge the role of applied behavior analysis as a theoretical and applied influence that converged, with the emerging recognition that students with moderate, severe, and profound disabilities could be educated. Applied behavior analysis (ABA) provided the power of systematic instruction and the instructional methodology that supported the learning needs of this population.

Historically, the first application of behavior analysis was conducted by Fuller in 1948. Fuller (1949) investigated the learning potential of an 18-year-old individual who was labeled profoundly retarded. He was described at the time as a "vegetative idiot." Through the systematic application of contingent reinforcement of arm movements, Fuller was able to increase their rate. Arm movements increased when reinforcement was delivered contingently and decreased when reinforcement was terminated. By the mid to late 1950s, demonstrations of the practical application of behavior analysis were conducted with several clinical populations.

By 1974, there were approximately 200 studies that had been reported in the literature demonstrating the successful application of behavior analysis in instructional and clinical settings involving children with severe behavior disabilities (Kazdin, 1978). These studies led some educators and advocates to believe that the learning potential of children with severe and profound disabilities was much greater than that even demonstrated to date. Simultaneously with the emergence of an effective pedagogy for teaching these children, parents and advocates turned to the legal system to secure the right to an education for children with severe disabilities.

Impact of PARC

The most significant court case that provided the precedent for educating children with severe disabilities in the public school and solidified the need for public policy leadership was Pennsylvania Association for Retarded Citizens (PARC). In 1971, PARC brought suit against the State of Pennsylvania, alleging essentially that the state was denying the right of education to persons with mental retardation. Pennsylvania lost the suit in federal court, and the resulting consent decree was that the state must provide a free appropriate public school education for all children with mental retardation.

The PARC consent decree brought the issue of the education of children with severe disabilities to the front door of the federal government. The Bureau of Education of the Handicapped (BEH) followed the developments of this landmark case. The Pennsylvania Association of Retarded Children consent decree had brought a whole new population to the Pennsylvania Public Schools. The BEH was concerned that if what happened in Pennsylvania was a forerunner of what was going to happen in the rest of the nation, the field of special education, the states, and the schools were largely unprepared. For the most part, children with severe disabilities were not served in public schools; many were served by local private agencies or resided in institutions, and many were not served at all because of waiting lists. In a 1975 speech at the first meeting of the American Association for the Education of the Severely/Profoundly Handicapped, Ed Sontag recalled that "the field was

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generally caught unprepared for the demands that were placed upon it to facilitate education of the severely handicapped child previously excluded from public education" (Sontag, 1976).

In late fall of 1972, Edwin Martin, Director of the Bureau of Education of the Handicapped, convened a meeting to discuss the implications of the PARC consent decree. In attendance were Edwin Martin, Robert Herman, Bruce Balow, Philip Burke, Jack Jones, Max Mueller, Paul Thompson, Ed Sontag, and Herb Goldstein. With the exception of Goldstein, all represented the leadership of BEH, whom Martin had brought together to focus on the Pennsylvania situation. Goldstein, the court-appointed master in the PARC case, was present to outline what the implications of the case were for the field of special education and what BEH could or should do to help Pennsylvania deal with the situation. The meeting focused on two main topics: (a) the increased cost of services for children with severe disabilities to the state and (b) the need for personnel to teach this population coming into the Pennsylvania public schools for the first time. The group presented various plans to deal with the financial issues. In addition, special attention was given to the needs of the Philadelphia schools and a visit was arranged to the Pennsylvania Department of Education and the Philadelphia Public Schools.

The participants focused a great deal of energy on the state's personnel needs. They agreed on the need to begin training new personnel to work with this population of children. Sontag's role in the Division of Training at BEH was to develop training for state education agencies and for the education of children with severe disabilities. One of the recommendations that emerged from the discussion was to begin training a new cadre of personnel who would, essentially, be paraprofessionals. That is, the initial reaction to the need for personnel was to create a teacher for children with severe disabilities who would not need a baccalaureate degree and traditional certification.

Although 25 years later, many of us find such a concept offensive to our present values and understandings, the context of the time helps explain the recommendation. In 1972, few public school systems had services for children with moderate, severe, or profound mental retardation, and many of these children were still served by private facilities or remained in institutions. At the same time, our nation's schools were emerging from a value system in which teachers with a masters degree were primarily employed at the high school level and teachers with a bachelor's degree at the elementary level. In addition, many in the field of special education generally believed that children with severe disabilities were not capable of learning much beyond rudimentary self-help skills. Therefore, it was not unusual that policymakers would seriously consider that paraprofessionals should teach this group of children.

After a series of meetings, however, the federal leadership within the Division of Training Programs, BEH, which included the newly appointed director, Richard Whelan, Philip Burke, and Ed Sontag, began to advocate for comparability in teacher standards, that is, for professional educators. After several months of internal debate at the federal level, Edwin Martin, the director of BEH, sanctioned the professionalization of teachers of children with severe disabilities and urged Sontag to continue to monitor the Pennsylvania situation and to begin developing a professional constituency to advocate for the education of these children. This advice, so typical of Martin, ultimately led to Sontag's focus on this population as his major interest for the next 3 years in BEH. In keeping with the focus, he made several trips to Pennsylvania, including many visits to the Pennsylvania Department of Education and the Philadelphia Public Schools.

The critical fallout of PARC, as conceptualized by Sontag, was two primary issues: (a) the lack of a performing community (i.e., scholars and practitioners) and (b) a sense that children with severe disabilities could learn much more than the field thought possible at the time. These two issues became inseparable. In December 1972 Whelan convened a meeting of the federal policymakers (Sontag, Jack Jones, Robert Dantona, Josephine Taylor, Paul Thompson, Philip Burke, Herman Saettler) and leading university scholars and trainers (Sam Ashcroft, Bill Bricker, Lou Brown, and Verna Hart) to discuss the training needs of personnel to serve this new population of students.

Several major points emerged. First, the group recognized that the field was unprepared for the entry of children with severe disabilities into the public schools and that what the field construed to be children with severe disabilities was quite different from the population coming into the schools. For example, in a 1971 grant announcement, the BEH defined the "most severely handicapped children as . . . the trainable retarded" (BEH, 1971, p. 2). Second, the group discussed at length and agreed that the Bureau needed to develop a two-prong strategy for this situation: (a) an immediate strategy of funding inservice programs and (b) a long-term strategy of creating new doctoral training programs. The doctoral training recommendation grew out of the sense that the current special education training programs were not sufficient to train the new breed of personnel needed. Brown suggested we needed to put the field on notice that "business as usual" would not be the appropriate answer. This meeting served both to galvanize the Bureau's actions and to create positive momentum.

From this meeting, the Division of Training Programs shifted into providing additional fiscal resources for the newly created target — "the severely and profoundly handicapped." In addition, other divisions in the BEH that had discretionary resources began to focus their priorities on this area. The Division of Research also adopted priorities for this population, stating in an informal document distributed to the field that their main priority was "to encourage additional educational programming to severely handicapped children to enable them to become as independent as possible, thereby reducing their requirements for institutional care and providing opportunities for self development." The Division of Assistance to States established

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a demonstration program for children with severe disabilities. Under the leadership of Paul Thompson, the first wave of new demonstration programs was funded in 1973. The Bureau took action under Edwin Martin's leadership, who prodded those in the federal service and fostered the development of the field of "the severely handicapped." His enlightened leadership was significant and, in many ways, was responsible for the establishment of AAESPH.

Clearly, the issue of providing educational services for children with severe and profound disabilities was becoming a focal point of the BEH agenda. The field responded to the priorities, so that by 1974 a performing community had begun to be identified and the first wave of doctoral students specializing in this area had begun their studies. School districts and universities began to see this population as part of their responsibilities.

The PARC and the *Mills* litigation established the precedent for the necessity for public schools across the nation to provide educational services for children with severe and profound disabilities. There were no examples of "good programs" providing comprehensive services for students who were violently aggressive, self-abusive, medically fragile, or without bowel and bladder control (Sontag, Burke, & York, 1973). Many state directors and local directors of special education began searching for ways to avoid serving these children; however, educators began exploring options for serving all children.

Sontag et al. (1973) published the first article that provided a helpful conceptualization to meet the challenge. In this article, six major goals were delineated:

1. To develop relevant and efficient preservice and inservice teacher training programs;
2. To develop highly specialized doctoral-level personnel with expertise in teacher training, research, and instructional design;
3. To develop and disseminate a more efficient instructional technology, instructional content (scope and sequence), and instructional materials;
4. To develop parent training programs enabling parents, in collaboration with teachers, to prepare their children with severe handicaps for school and work;
5. To develop relevant vocational skill training programs;
6. To develop life-encompassing service plans, so that after 15 or 18 years in a public school program, students could avoid spending the remainder of their lives in residential institutions (pp. 25-26).

In addition, the notion of inclusion into neighborhood schools was invoked by following "dispersal approaches" for serving children with severe disabilities:

1. The programs for students with severe handicaps would be represented in nearly every school, making contact with regular educational programs, personnel, and students the norm. Integration of persons with severe handicaps into the community and acceptance of these students would be enhanced by this widespread mutual contact of regular education and special education students.
2. Despite grouping by functional level, which must be utilized in the school system, most children would be placed in schools near their homes. School placement in close proximity to a student's home may yield the advantages of convenience, fewer transportation problems, superior community acceptance and adjustment, and so forth. (Sontag et al., 1973, p. 20)

Sontag, who became a Branch Chief in the Division of Personnel Preparation at BEH, decided that an organization for persons with severe disabilities was needed critically. In the spring of 1974, in Albuquerque, New Mexico, Sontag discussed with Haring the notion of establishing an organization to support the delivery of quality services to children with moderate, severe, and profound disabilities. Sontag argued that the major organizations in the field of special education and mental retardation at the time were either not interested in this population or remained ambivalent about whether or not the children could benefit from educational service. Haring agreed that the timing for a national organization to provide education, research, and methodologies was ideal. Because of his academic credentials and recognition within the field of special education, Haring was asked to provide the high profile leadership the movement needed. Haring, as the Director of the Experimental Education Unit, University of Washington from 1965, had 12 students with severe disabilities enrolled in a demonstration program. It was clear, as Haring recalls, that his experience with deinstitutionalization in the state of Washington during the 1960s had illuminated the disadvantages of the extreme disorganization that can occur without a systematic program supporting new efforts such as this one.

Sontag and Haring concluded that a new special organization would be a practical way to gain immediate attention to the needs of these students. Sontag pointed out that many project directors of the BEH-funded research and demonstration programs for children with severe and profound disabilities would be meeting in Kansas City in November 1974, and that this group would provide an excellent audience for considering the proposal to start a new organization. This meeting would bring together many professionals throughout the country most knowledgeable about the learning potential of students with severe disabilities.

The meeting convened at the University of Kansas Medical Center on November 14, 1974. Sontag opened the meeting by thanking the nearly 60 individuals who attended for giving their time. Then, he suggested that the group consider establishing its own professional organization, and further, that this political action be taken at the end of the Bureau's meeting so as not to invoke criticism for using government resources to establish an organization.

TASH Was Formed in a Smoke-Filled Room

On the evening of November 14, 1974, approximately 30 participants of the First Annual Seminar of Research and

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Demonstration Programs for Severely/Profoundly Handicapped Children and Youth attended an evening meeting that continued until after midnight. After an informal discussion, the group suggested that Alice Hayden, Associate Director of the Experimental Education Unit, University of Washington, and Director of the Model Preschool for Handicapped Children, serve as chairperson. Hayden opened the formal meeting with the issue of forming an organization that would focus on research, service, and the preparation of personnel for educating "the severely handicapped." The motion was made and seconded "to form an organization for persons with severe handicaps." The participants recommended that the organization assume responsibility for the following activities:

1. Development of a newsletter to facilitate open communication among members.
2. Establishment of a mechanism for disseminating research activities.
3. Development of opportunities for facilitating professional preparation.
4. Provision of opportunities for exchanging information about effective intervention programs.
5. Strengthening of political activities on behalf of persons with severe handicaps.

The immediate need for starting a new journal was suggested; however, an urgent need was recognized for members to supply articles to journals already established. In addition, the group identified an immediate need to provide consistent, basic, and high-quality educational programs for students with severe disabilities. The discussion emphasized the goal of providing a way to establish and strengthen the functional responses of individuals with severe disabilities leading toward independence and an increased quality of life. To meet this goal, the group recommended that (a) systematic instructional procedures and materials be developed and (b) a way of disseminating the materials and procedures to professional personnel throughout the country be provided.

A motion was made to form a subcommittee responsible for refining the goals of the organization, naming the organization, and nominating officers and an executive board *pro tempore*. By early morning November 15, 1974, the subcommittee's proposal to organize a nonprofit association named the American Association for the Education of the Severely/Profoundly Handicapped (AAESPH) was approved by the members of the larger group that remained. In addition, a slate of temporary officers and an executive board were elected on a *pro tempore* basis. Elected officers were Norris Haring, president; Lou Brown, vice-president; Frances Anderson, secretary; and Bob York, treasurer. The executive board included Diane Bricker, Marilyn Cohen, Laura Dennison, Marc Gold, Doug Guess, Wayne Sailor, and Richard Whelan. That afternoon, the small steering committee completed the following statement of the association goals:

1. To function as an advocacy organization for the development and implementation of comprehensive, high-quality educational services at birth through adulthood in the public sector.
2. To serve as a separate entity in advocating for:
   a. the development of relevant and efficient preservice and inservice teacher training programs;
   b. the development of highly specialized doctoral-level, teacher training, research and instructional design personnel.
3. To develop, refine, and disseminate training packages, instructional programs, and materials.
4. To facilitate parental involvement in all program services for the severely and profoundly handicapped.

In the time between Sontag's proposal to establish a new organization and the first official meeting, Haring arranged to support some dissemination activities that ultimately became the activities of the new organization. This led to the first official meeting.

The first official meeting of AAESPH (TASH) was November 12-14, 1975, in Kansas City, Missouri. The board members of the newly incorporated AAESPH were confirmed and introduced by Doug Guess as follows: Vic Baldwin, Diane Bricker, Lou Brown, Tim Crowner, Marc Gold, Norris Haring, Verna Hart, Alice Hayden, Camille Peck, Wayne Sailor, Ellen Somerton, Jim Tawney, Dick Whelan, Wes Williams, and Bob York. The Executive Committee officers elected by the board were Norris Haring, President; Diane Bricker, Vice-President; Verna Hart, Secretary; Bob York, Treasurer; and Alice Hayden, Chairperson.

In Haring's welcoming address, he referred to the meeting as the second annual conference, however, the organization had not been incorporated at the time of the 1974 Kansas City meeting (Haring, 1977). In his address, he listed the goals that were similar to, but somewhat refined, from the 1974 meeting. From 1974 to 1975 the association grew from the 32 original members to approximately 1,200. Individuals who joined during that year represented significant diversification, such as public school administrators, teachers, professionals from residential institutions, students, and parents.

The membership grew by word of mouth and through specific invitations from the 32 members of the first meeting. There was a great amount of resistance to the establishment of the organization. Members of the group who promoted the organization were ignored, even ridiculed, in some cases, by their own colleagues. During that period, it was common for medical practitioners to advise parents who had infants with Down syndrome and severe disabilities to place their children in residential institutions. The concern was that maintaining children with moderate and severe disabilities in the home was a formidable problem. The National Institute for Education prepared a report to present to Daniel Moynihan, for President Ford, on the school desegregation issue. That report raised real questions about the value of early educational intervention, suggesting that school intervention in early childhood has little, if any, long-term effect on achievement.

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Pursuing the issue of the value of intervention in general, Haring stressed the urgent need for measurable results of gains provided by systematic intervention. Certainly, the procedures for strengthening the performance of children with severe disabilities had been demonstrated. We then had to demonstrate that the goals we had established were functional and that we could quantify the gains made as a direct result of intervention.

Haring concluded his remarks at the 1975 Kansas City meeting by stressing that the effectiveness of educational programs then implemented for students with severe disabilities would depend upon systematic procedures, a curriculum based on teaching functional skills, and the positive attitudes and support of the individuals in the lives of these students.

The keynote address was delivered by Ed Martin, Deputy Commissioner of Education, U.S. Office of Education. In his address, Martin attributed great significance to the Association because it was organized to devote specific attention to the affirmation of rights of each and every individual. Martin outlined four major considerations that had to be addressed to forge ahead in serving this seriously underserved population (Martin, 1975):

1. We must learn more about how to teach the children — what sparse course offerings available for training professionals are offered by teachers who are themselves without sufficient expertise. We must become more functional in the way we prepare teachers and instructional support staff.
2. Because teaching children with severe disabilities is a demanding task, we must provide teachers with stronger support systems, working directly with them as support in their classrooms.
3. We must place greater emphasis on measuring incremental change in behavior toward the specified instructional objective; and, further, it is essential to develop a system of evaluation to assist teachers in making more accurate instructional decisions.
4. Providing comprehensive instruction and management for these children and youth necessitates the collaborative efforts of a number of disciplines ... teachers and therapists working smoothly together. The thought that each discipline is more vital than the other is totally nonfunctional in this endeavor.

A third major address was delivered by Sontag. In his speech, he enumerated four major developments that emanated from the PARC decree and *Mills v. Board of Education of the District of Columbia*. These major developments included a significant attitude change within the special education community. Before PARC, school officials justified excluding children with severe disabilities from services. By 1975, educators were beginning to recognize that:

1. All children had a right to an education.
2. The focus of services for students with severe disabilities had been shifting from institutions to special programs in local schools in self-contained classrooms.
3. Early childhood programs for preschool children with severe disabilities were being established throughout the country. In 1972 there had not been one professional preparation program for teachers of students with severe disabilities.
4. The Division of Training Programs began providing financial support through grants to training programs for fellowships in leadership training programs in severe disabilities.

Although Sontag readily acknowledged accomplishments that had been achieved in the four years since the PARC decree, he identified four concerns that needed serious consideration for improvement. First, he proposed that we conceptualize a new model — "a model that calls for more integration into the regular public schools of the severe and profoundly handicapped child" (Sontag, 1976, p. 2).

Second, Sontag suggested that special education should strengthen its role in developing parent-professional partnerships. Parents and professional partnerships could improve significantly the educational alternatives for children with handicaps and, in the end, provide for better quality of services to children with severe disabilities.

Third, there was a dire need to build new programs for infants and young children and strengthen those that currently existed. It was crucial that we concentrate on very early identification of infants who were at risk for disabilities, so that timely, systematic intervention could begin.

Finally, as professional interactions over the several disciplines were expanded, there was a need to standardize communication among those involved in comprehensive management (Sontag, 1976).

Epilog

It was our vision in 1974 to create an organization that was unique and would make a difference in the lives of children with moderate, severe, and profound disabilities. We succeeded in establishing a professional community recognized for excellence in the education of these students. The principles under which this organization was established are as viable today as they were then. The outstanding leadership that emerged out of the federal efforts collaborating with the academic and advocacy communities is a testament to the success of the movement. This article chronicles the period preceding the creation of TASH. Perhaps others will follow to document the growth, accomplishments, and success of this organization.

FOOTNOTE:

1 Following the PARC suit was the action filed in the District of Columbia (*Mills v. Board of Education of the District of Columbia*, 1972). This decision expanded the right of an education to all children with handicaps. In addition, it stated that the District of Columbia School Board must not take any actions that would exclude children with disabilities from a regular public school placement, and, in case such placement was not available, must provide students with alternatives at public expense. The Mills decision ruled out any reason, including insufficient resources, for not providing public school education for all children and youth with disabilities.

Continued on page 31

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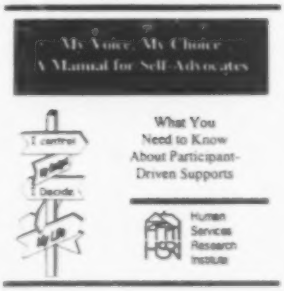
By John Agosta, Kerri Melda & Cathy Terrill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JUSTIN DART
Co-Founder, Justice for All

Although I was not associated with TASH during its early days in the '70s, I have come to know the organization well as a group of passionate, cutting-edge advocates for empowerment, rights and services for people with significant disabilities. I believe so strongly in the work of the organization that I became a lifetime member several years ago.

TASH has expanded my consciousness to understand human development much better. The passionate people of TASH have expanded my passion to fight for life. TASH policy and advocacy has produced miracles in the lives of people thought to be physically, mentally and economically hopeless. TASH has expanded the horizons and quality of human life.

TASH should continue its dynamic leadership role. TASH should expand its membership ten or a hundred times. TASH should get its members into politics. Some of our most serious problems will never be solved until we replace certain demagogues with people who believe in the inclusive democracy of Jefferson, Lincoln, FDR and Martin Luther King.

Justin Dart with staff member, Don Dotson (right) and his son, Matthew, at TASH's September, 1998 IDEA Rally in Washington, D.C.

Reflections By An Early Leader of TASH

MARTI SNELL

My Involvement with TASH

When TASH was started, I had just completed one year of teaching at the University of Virginia in the Curry School of Education and a year prior to that at Michigan State University. I was relatively young — 28 years old. During the summer of 1974 I was involved in post-doctoral study under Diane and Bill Bricker at the Mailman Center at the University of Miami. I saw Diane after she had attended an organizational meeting for AAESPH (the American Association for the Education of the Severely/Profoundly Handicapped, later renamed TASH) and I asked her what the lengthy acronym meant on a button she wore. She told me all about the group, the active role of Alice Hayden (senior faculty member and one of the main organizers of TASH) along with other early founders and members of the association: Norrie Haring, Wayne Sailor, and Lou Brown. I knew all their names but had not met any of them and was eager to join as Diane elaborated on the goals of the group.

Initial Meeting of AAESPH

The first meeting I attended was the following Fall of 1974 in Kansas City. Was it Jimmy Carter, presidential candidate who walked through at the time we were meeting? I think so, but my memory is a bit fuzzy.

My involvement with TASH did not occur until several years later when I became a member of the board. My resume includes the following lines about my long-term and meaningful involvement with TASH: The Association for Persons with Severe Handicaps (TASH) (Lifetime Member; Executive Board Member, 1979 to 1991; Treasurer, 1980-1981, 1983-1984; Vice President, 1984 to 1986; President-Elect, 1986 to 1987; President, 1987 to 1990; Member, Publications Committee, 1990 to present; Personnel Preparation Committee, 1990 to 1996; Membership Operating Committee, 1997 to present).

The earliest TASH board meetings were lively and never boring (not that today's are unlively or boring - I have not been to a board meeting for a while!). Our meetings stretched out all day and sometimes longer, but we had great debates and interchanges among us. Liz Lindley told me years later that she stopped serving caffeinated coffee at board meetings after the first pot was done — she thought we got too lively. Carving out the first resolutions was central in these meetings. Lou Brown's sense of humor and strong convictions on many key concepts such as functionality, age appropriateness and segregation served as a visible banner we all looked toward in our early meetings. In later meetings, Luanna Meyer seemed to define and hold steadfast to the "purest" TASH position, often being a leader in establishing standards for the board.

While our early meetings were highly stimulating and productive, they also were relaxed in procedures, perhaps too relaxed, a problem that we eventually faced as we grew larger. As time progressed, many of us learned how to better fill board member responsibilities.

TASH's Role in the Disability Advocacy Field

TASH has always been viewed as radical — a judgment that made us proud. It was not until later that our early radicalism seemed not to keep up with our members' radicalism at times. For example, our policies not to advertise any schools/programs that were segregated was unmatched in the nonprofit world of organizations. Likewise, our practice not to admit presenters who espoused views that were counter to our resolutions (pro-aversives or institutions, for example) was strong and consistent for years, but challenged at times by outsiders crying "freedom of speech" and some members who wanted less purism.

The State of Disability Rights in the 1970s

Institutions were still taking people into their folds and only infrequently releasing them. Virginia was a "leader" in this practice. Like many early TASHites, I had come from a history associated with institutions. My life before Virginia was in Michigan and my start in special education was at the Plymouth State Home and Training School as a child care worker. This institution closed in the late 1970s while Virginia's institutions added new beds and continued to practice sterilization of people with mental retardation with a law in support of this practice on the books until the early 1980s! The then Lynchburg Training School and Hospital (an hour south of Charlottesville) had a population of 3,000 in 1973, the largest in the country.

Inclusion was not practiced nor even known as a term; mainstreaming was only for those with the mildest disabilities and meant earning one's way back into "regular" education; collaborative planning was not a required practice, and none of this applied to students known as TMR, low functioning, or severely and profoundly mentally retarded (as those with severe disabilities were referred to). People-first language was

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unheard of, as was supported employment, transition plans, and IEPs. Things were pretty primitive both in terms of practices that promoted normalized lives and attitudes toward people with disabilities.

TASH's Importance in the Disability Field

I think TASH has been highly influential in this country, though in gradual ways and in ways that may not link directly back to us. Our influence has been in the areas we have most consistently believed in, preached on, practiced, written about, and researched. These areas are:

- the elimination of segregated public schools
- the closing of institutions;
- the banning and replacement of aversive interventions with positive behavior support;
- the design of instructional programs that are functional and age appropriate;
- the promotion of meaningful participation, even if partial;
- the promotion of integrated therapy;
- the use of people-first language; and
- the promotion of inclusive school programs.

Today, compared to the 1970s, educational practices, special education laws, and philosophies are vastly different. I think these changes are a result of our influence both on others and on each other. In many cases, in the early years we pushed each other into new ways of thinking about the people we worked with who had severe disabilities, our debates refined and strengthened our thinking and set the beginning standards for TASH.

I continue to be surprised by the conservative nature of other disability organizations, and also by the way they seem to follow in our wake (though most would never admit it!), many groups often years behind us. I think this is more evidence of our ability to take the lead. We have been called many names (e.g., Doug Fuchs referred to us and Dianne Ferguson as the radical inclusionists), most of which we are pleased with.

Currently, my philosophy and my advocacy role continue to be consistent with that of TASH, though I play a far less active role in the organization.

How TASH Has Impacted the Lives of People with Disabilities

TASH's work and the leadership role of the association has had both direct and indirect impact on the lives of people with disabilities and their families in several key ways including:

- Reducing the institutionalization of people with disabilities and closing institutions;
- Influencing current legislation such as supported employment and transition laws and the inclusion of positive behavior support in the 1997 IDEA;
- Increasing the practice of integrated therapy;
- Influencing instructional practices for students with severe disabilities (e.g., age appropriate, functional, use of ecological inventories, community-based instruction, etc.);
- Increasing inclusive school practices for students with severe disabilities through the efforts of the TASH membership and their published research, published texts, court cases, and exemplary school practices.

The positive outcomes of TASH's work and influence are most evident as TASH values have impacted upon and shaped my own professional values. These values have in turn influenced my daily teaching of university students, my writing and research, and my role with local, state, and national organizations. The negatives were at a peak when I was near the end of my tenure as president and the politics of TASH were at a very high stress point for many of us as many changes were being made in our organization. I remember sometime earlier in the mid-1980s when my involvement competed with my role as mom of two young girls. My youngest daughter, Claire, was about 4 or 5 years old (she attended the Colorado meeting as an infant, a real hit at the cocktail party). She accompanied me to the car as I headed out for another TASH meeting (I believe the Spring meeting of the board). She looked at me scowling and said, "I hate TASH." But today both my kids know to use people first language and have values on disability consistent with TASH values.

I would call TASH an advocacy organization, not a professional organization, though professionals may make up the majority of the association's membership. Advocacy for people with severe disabilities and change to benefit them and their families is — and always has been —our purpose.

Future Directions for TASH

First is TASH's devotion to improvement for people with severe disabilities and its nature of self-examination and challenge. I think we need to continue and/or strengthen:

1. The association's influence in Washington;
2. The productivity of our membership: writing through our newsletter and research in our journal;
3. The association's impact on a state level through TASH chapters;
4. The writing and publication of TASH books and monographs;
5. The organization's impact in important court cases through organization and strategizing via TASH meetings and members (e.g., Frank Laski and Lou Brown have been central to this process);
6. TASH's linkage and influence with other disability organizations;
7. The association's informative and powerful conferences.

An Introduction To Disability Studies

BY PERRI HARRIS AND LORI LEWIN

Over the past several decades, what we now refer to as "Disability Studies" has been a powerful influence on policy and practice in regard to people with disabilities. Disability Studies has evolved as a means of addressing how people with disabilities have been treated historically and how they continue to be treated. Once seen through a medical model as people who are sick and in need of a cure, through a sociological model where people with disabilities are labeled and stigmatized by others, or through a psychological model where their experiences have been individualized and pathologized, people with disabilities are now being seen through different perspectives. Although medical and psychological models are still present, they are being resisted by a relatively new field called Disability Studies, premised upon the philosophy that disability is a social construction. While Disability Studies does not deny that there are differences, either physical or mental, between people, they argue that "the nature and significance of these differences depend on how we view and interpret them" (Bogdan and Taylor, 1994). Therefore, rather than seeking to "fix" a person or to separate him or her from the rest of society, a Disability Studies perspective would seek to "problemitize" society rather than the individual. The solution therefore lies not in the person, but rather in breaking down the barriers that limit people with disabilities from full participation in their communities and in society in general.

Disability Studies seeks to examine the social, economic, and political forces that for years have served to marginalize and oppress people with disabilities. The field has emerged over the last several years, drawing on theories and perspectives from sociology, social science, womens studies, cultural studies, and education. It often focuses on the idea that people with disabilities are a minority group who have been discriminated against. In this sense, the study of disability is similar to the study of race, class, and gender inequalities. In addition, Disability Studies provides the intellectual and methodological tools needed to create disability research and policy. The theories and philosophies of Disability Studies can then be applied to real issues in the law, in community inclusion, and in public policy.

The field of Disability Studies continues to grow and change. Recent additions to the field such as feminist Disability Studies and cultural studies have challenged "traditional" Disability Studies, and have forced the field to be more inclusive of different perspectives and positions in society. Moreover, Disability Studies most often focuses on issues around people with physical, rather than cognitive disabilities. One major challenge for the future of Disability Studies is the inclusion of the experiences of people with cognitive disabilities and how they shape this emerging field.

Reference

Bogdan, R., & Taylor, S. J. (1994). *The social meaning of mental retardation: Two life stories.* New York: Teachers College Press.

• • •

SELECTED ANNOTATIONS OF DISABILITY STUDIES TEXTS

The following listing is comprised of books that could be used as "text books" for a Disability Studies course. Most of them are edited books (there are some articles) that cover a variety of topics such as disability rights, identity politics, cultural studies and disability, social perspectives on disability, and perspectives of people with disabilities. It is worthy of note that the majority of this material is written from the perspective of or includes the perspective of only those with physical disabilities. Unfortunately, over the past several years, "texts" such as these which include developmental disability and Disability Studies have not been published.

• • •

Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment.* Berkeley, CA: University of California Press, 2120 Berkeley Way, Berkeley, CA 94720, FAX 510-643-7127, http://www-ucpress.berkeley.edu/

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An Introduction to Disability Studies

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The author uses a disability rights standpoint to discuss the international oppression of people with disabilities. He provides a theoretical framework for understanding disability oppression not as something that has come from the attitudes of people without disabilities, but because of systems and structures of oppression from which these attitudes stem. He uses interviews with disability rights activists from around the world to support his argument.

• • •

Crossley, R. (1997). *Speechless: Facilitating communication for people without voices*. New York: Dutton, Penguin USA, 375 Hudson Street, New York, NY 10014, http://www.penguin.com

Rosemary Crossley has been a pioneer of and outspoken advocate for facilitated communication since the 1970s. Her recent book, *Speechless: Facilitating communication for people without voices*, is an in-depth look at the experiences of 18 individuals who use facilitated communication. She describes the frustrations and complexities they face in their attempt to make themselves understood by others in their environment. She also explains the process of using facilitated communication, answering many of the questions raised about FC and demystifying many of the aspects of it that have troubled others.

• • •

Davis, L. J. (Ed.). (1997). *The Disability Studies reader*. New York: Routledge, 29 West 35th Street, New York, NY 10001, 212-216-7800, FAX 212-564-7854, http://www.thomson.com/routledge

This edited reader is a collection of classic and new essays, as well as fiction and poetry, in the field of Disability Studies. This perspective places disability in a political, social, and cultural context that theorizes the construction of disability in this society. The authors address such areas as feminist theories of disability, the construction of deafness, and disability as metaphor. The book is divided into seven sections, including historical perspectives, politics of disability, stigma and illness, gender and disability, disability and education, disability and culture, and fiction and poetry. This is progressive reading, but it should be of note that it is traditional in the sense that Disability Studies translates to "physical Disability Studies" and there is little mention of developmental disability.

Fries, K. (Ed.). (1997). *Staring back: The disability experience from the inside out*. New York: Plume, Penguin Putnam Inc., 375 Hudson Street, New York, NY 10014, http://www.penguin.com

This book, edited by Kenny Fries, explores the experience of disability through writings by contributors who have disabilities. The collection includes nonfiction, poetry, fiction, and drama by such authors as Nancy Mairs, John Hockenberry, Anne Finger, Adrienne Rich, Mark O'Brien, and Marilyn Hacker. Each chapter explores disability not as something that limits one's life, but as an experience all its own. Fries considers the theme of this edited book as one of human connection, "connection with the past, connection with one another, connection with our bodies, connection with ourselves."

• • •

Eiesland, N. (1997). *The disabled God: Toward a liberation theology of disability*. Nashville, TN: Abingdon Press, 201 Eighth Ave. South, P.O. Box 801, Nashville, TN 37202-0801, 1-800-251-3320

Through this book, Eiesland, who became disabled as a child when she had polio, helps the reader to see how the "hidden history" of conventional bodies living ordinary lives with grace and dignity, disgust and illusion, can make for both a theological and pastoral contribution. Arguing for a liberation theology, she calls on us to move away from our defining of people with disabilities as people who need to adjust to a minority group that is subject to social stigmatization. While her examples tend to be based on the experiences of people with physical disabilities, what she has to say also is insightful for those working to include people with developmental disabilities in faith communities.

• • •

Ingstad, B., & Whyte, S. R. (Eds.). (1995). *Disability and culture*. Berkeley: University of California Press, 2120 Berkeley Way, Berkeley, CA 94720, FAX 510-643-7127, http://www-ucpress.berkeley.edu/

This edited book takes a global look at disability. Each chapter reflects understandings of disability from different cultures. Its anthropological focus examines the relationship between disability and culture, explaining disability in terms of social processes from a multi-cultural perspective. Contributing authors, who have done research in places such as Borneo, Kenya, Uganda, Nicaragua, as well as Europe and North America, explore the meanings of different types of disabilities to different cultures, and seek to understand the assumptions about humanity and personhood derived from their understandings of disability.

Continued on page 21

An Introduction to Disability Studies

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Johnstone, D. (1998). *An introduction to Disability Studies*. London: David Fulton Publishers Ltd., Ormond House, 26-27 Boswell Street, London WC1N 3JD UNITED KINGDOM

The study of disability as an academic subject is of relatively recent origin. Disability Studies has emerged as a discipline for academic study in universities over the course of the last decade. This book sets out to explore in a straightforward manner some of the themes that link Disability Studies with wider explorations of equal opportunities and social justice.

• • •

Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York: New York University Press, 70 Washington Square South, New York, NY 10012-1091, 1-800-996-6987, FAX 212-995-3833, E-Mail: orders@nyupress.nyu.edu, http://www.nyupress.nyu.edu

In this book, Simi Linton studies disability in relation to identity. She argues that Disability Studies must understand the meanings people make of variations in human behavior, appearance, and functioning, not simply acknowledge that these variations "exist." Linton explores the divisions society constructs between those labeled disabled and those who are not. She avoids a medicalized discussion of disability and promotes the notion that people with disabilities need to claim their identities as disabled and as contributing members to the understanding of disability as a socio-political experience.

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Linton, S. (1998). Disability Studies/Not Disability Studies. *Disability & Society, 13*(4), 525-540.

In this article, Simi Linton seeks to define the boundaries between what should be considered Disability Studies and what should not. For reasons that she outlines, she proposes that curriculum and research that emphasize intervention should be viewed as separate from disabilities studies, which is a socio-political-cultural examination of disability. Linton advocates a liberal arts-based model similar to that which frames women's studies and African-American studies.

• • •

Mitchell, D. T., & Snyder, S. L. (Eds.) (1997). *The body and physical difference: Discourses on disability*. Ann Arbor: The University of Michigan Press, 839 Greene Street, P.O. Box 1104, Ann Arbor, Michigan 48106-1104, E-Mail: umpress-www@umich.edu, http://www.press.umich.edu/

This edited book by Mitchell and Snyder seeks to introduce Disability Studies to the humanities by exploring how writers have used physical and cognitive disabilities in literature. The chapters explore how disability is seen in our culture in relation to "aberrance" and "normalcy," and explores the meanings of health, the construction of the body, citizenship, and morality in relation to disability. The authors present a variety of literary perspectives in two parts. Part I is "Representations in History," and chapters include such topics as "Constructions of Physical Disability in the Ancient Greek World: The Community Concept" by Martha Edwards, "Defining the Defective: Eugenics, Aesthetics, and Mass Culture in Early Twentieth-Century America" by Martin S. Pernick, and "Conspicuous Contribution and American Cultural Dilemmas: Telethon Rituals of Cleansing and Renewal" by Paul K. Longmore. Part II is "A History of Representations," and includes chapters such as "Feminotopias: The Pleasures of 'Deformity' in Mid-Eighteenth-Century England" by Felicity A. Nussbaum; "The 'Talking Cure' (Again): Gossip and the Paralyzed Patriarchy" by Jan Gordon; and Disabled Women as Powerful Women in Petry, Morrison, and Lorde: Revising Black Female Subjectivity" by Rosemarie Garland Thomson.

• • •

Nagler, M. (Ed.). (1993). *Perspectives on disability (2nd ed.)*. Palo Alto, CA: Health Markets Research, 851 Moana Court, Palo Alto, CA 94306

In this second edition edited by Mark Nagler, he once again explores the meaning of disability in our society. Using an interdisciplinary perspective, he offers articles by sociologists, psychologists, therapists, and others to explore the ways in which disability is constructed and understood. The book includes a foreword by Evan Kemp Jr. and an introduction by Nagler. He divides the book into the following sections: "What it means to be disabled," "Society and disability," "The family and disability," "Sexuality and disability," "Medical and psychological issues and disability," "Education, employment, social planning and disability," and "Legal and ethical issues and disability." The selections for this second edition are good, but there are not many articles relating to people with developmental disabilities. This is the one main weaknesses of this text.

Continued on page 22

An Introduction to Disability Studies

Continued from page 21

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Pelka, F. (1997). *The ABC-CLIO companion to the disability rights movement*. Santa Barbara: ABC-CLIO, INC., 130 Cremona Drive, P.O. Box 1911, Santa Barbara, CA 93116-1911, http://www.abc-clio.com/

This text is a general introduction to the disability rights movement and the people and court cases that support or challenge it. It includes entries on such people as Ed Roberts and Judy Heumann. The book is organized as a dictionary, and has references from every aspect of the disability rights movement, from court cases to famous people, to historical events and disability culture. It also includes a chronology, beginning with the founding of the American School for the Deaf in 1817 and concluding in 1996.

• • •

Schlesinger, L., & Taub, D. (Eds.). (1998). *Teaching sociology of disabilities*. Washington, DC: American Sociological Association (ASA) Teaching Resources, 1722 N Street, N.W., Washington, DC 20036, http://www.asanet.org

Teaching sociology of disabilities is a collection of syllabi and instructional materials on disability issues. It can be purchased by ASA members for $17.00 and by non-ASA members for $21.00. A copy can be downloaded from the ASA web site at no charge.

• • •

Taylor, S. J. (1996). Disability Studies and Mental Retardation. *Disability Studies Quarterly, 16*(3), 4-13. (For a copy of this article, call 1-800-894-0826)

This article applies a Disability Studies perspective to the study of people labeled as having mental retardation or cognitive disabilities and examines mental retardation as a social and cultural phenomenon. The article includes an extensive annotated bibliography on mental retardation and Disability Studies by Steve Taylor and Perri Harris.

• • •

Thomson, R.G. (1997). *Extraordinary bodies: Figuring physical disability in American culture and literature*. New York: Columbia University Press, 562 West 113th Street, New York, NY 10025, 1-800-944-8648, FAX 1-800-944-1844, http://www.cc.columbia.edu/cu/cup/

Thomson's book explores the field of Disability Studies by framing disability from a minority perspective rather than a medical one, revising oppressive narratives and revealing liberatory ones. Examines disability in Harriet Beecher Stowe's *Uncle Tom's Cabin*, Rebecca Harding Davis's *Life in the Iron Mills*, in African-American novels by Toni Morrison and Audre Lorde, and in the freak show.

• • •

This article includes excerpts from the Center's *Information Package on Disability Studies*. To request a complete copy, please call 1-800-894-0826 within the U.S. or 315-443-3851 all other areas.

• • •

Disability Studies at Syracuse University

The Disability Studies concentration applies social, cultural, historical, and philosophical perspectives to the study of disability in society. Consistent with the Syracuse tradition, this concentration stands at the forefront of change and new ways of thinking about and accommodating people with disabilities. While it adopts a cross-disability perspective, it devotes special attention to people who have been labeled as developmentally disabled or mentally retarded.

For further information about the Disability Studies concentration, please contact: Steven J. Taylor, Ph.D., Coordinator, Disability Studies Concentration at 315-443-3851 or via email at staylo01@mailbox.syr.edu

The preparation of this article was supported in part by the National Resource Center on Supported Living and Choice, Center on Human Policy, School of Education, Syracuse University, through the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133A990001. Members of the Center are encouraged to express their opinions; however, these do not necessarily represent the official position of NIDRR and no endorsement should be inferred.

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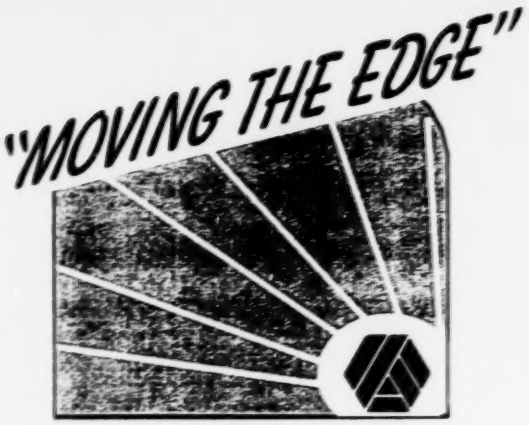

International TASH Conference
December 6-9, 2000
Fontainebleau Hilton - Miami

Call for Presentations

TASH is an international advocacy association of people with disabilities, their family members, community members, other advocates, and people who work in the disability field. Our members are working for a society in which inclusion of all people in all aspects of society is the norm. We are an organization of members concerned with equity, diversity, social justice, human rights, and inclusion for all.

2000 Priority Topics

Proposals may be submitted on any topic that relates to the inclusion of people with disabilities. Proposals will be rated by the interest areas listed on the form (page 3), however, The TASH 2000 Conference Committee has identified particular interest in the sub-topic areas listed below:

Advocacy
Building Alliances and Coalitions
Community Living
*Creative and Performing Arts
Communication
Criminal Justice
Curriculum Adaptation
Deaf Culture
Deaf/Blindness
Early Childhood
Educational Reform
Euthanasia Resistance
Employment and Careers
Family Issues
Functional Assessment for Behavior Change
Governmental Affairs
Grassroots Organizing
Guardianship Alternatives
Higher Education
High School Inclusion
Housing /Home of Your Own
IDEA Monitoring and Enforcement
IDEA '97 Regulations
Impacting Legislation
Inclusive Education Strategies
Independent Living Centers, Councils, or Services
Integrated Sports
International Inclusion
Internet and Disability
Issues of Death and Dying
Issues of World Peace & Social Change
Leisure and Recreation
Life Transitions & Changes in Supports for Aging Adults
Managed Care
Management Issues
Mediation
MiCASSA/Personal Assistance
Multicultural Issues
Paraprofessional Issues
Personnel Preparation
Positive Approaches to Behavior Change
Qualitative & Quantitative Research
Rare Syndromes
Rehab Act
Related Services in Inclusive Education
Self-Advocacy
Self-Determination
Special Health Care in Inclusive Settings
Sexuality, Romance, & Dating
Spirituality
Teacher Preparation
Transition from School to Work
Special Health Care Needs
Students Who Severely Challenge Schools But Who Do Not Have "Severe" Disabilities
Systems Change at the Local Level
Systems Change at the Policy Level
Urban Education Issues

** Please note: TASH will not be able to provide staging, lighting, etc. in session rooms.*

Guidelines for Submission

Send the Original and 3 copies of the Application and Abstract (postmarked) by March 20, 2000 to:

Kelly Nelson, TASH , 29 West Susquehanna Avenue, Suite 210, Baltimore, MD 21204

Questions? Phone: 410-828-8274 ❖ TDD 410-828-1306 ❖ Website: http://www.tash.org

Sorry, faxed or e-mailed copies cannot be accepted

1) ***All* presenters are required to pay conference registration fees.** TASH relies solely on membership and conference registration to be an effective advocacy organization. We strongly encourage presenters to be TASH members. TASH members, self-advocates, parents, and family members are eligible to register at a reduced rate.

2) **TASH encourages presentations that are made through partnerships.** Panels are also encouraged to represent multicultural, under-served, and varying socioeconomic viewpoints. Presentations for consideration in the Community Living Strand will *require* participation of self-advocates and/or family members for acceptance.

3) **Please complete all sections of the application. An abstract must be sent along with the completed application, postmarked by March 20, 2000.** Abstracts should (1) describe the topic or issue addressed, (2) provide an overview of the content, (3) describe the importance and contributions of the session, and (4) describe the session format - i.e. skill-building, program discussion, panel, etc.

4) **Proposal content must reflect the values and resolutions of TASH**. TASH is dedicated to disseminating information that reflects both the ideals and the pragmatic realities of pursuing the goals of equity, social justice, diversity, and full school, community, and work inclusion for people with disabilities. The proposal title, description, and all content of presentations must use "people first" language, and must relate to supports or issues that are community-based.

5) **Please limit the abstract to 300-600 words (1 - 1 1/2 pages).** Do not send any other materials. You may submit the information on the application form or in alternate format, as long as all of the information requested is included. The form is available to download from TASH's web page: www.tash.org. You must, however, print and mail the form as per the guidelines. Please **DO NOT** email your proposal, as we cannot assure receipt or legibility of electronic transmissions.

6) In requesting the session format, please keep in mind that 1 hour and 2 1/4 hour presentations slots are limited. **Poster sessions are "exhibits" that allow personalized opportunity for discussion.** These sessions are highly interactive and valuable.

7) Once received, abstracts are forwarded to three reviewers for scoring. **Proposals are rated on the following criteria:** 1) relevance to TASH mission, 2) interest to TASH members, 3) extent to which information is state-of-the-art, or cutting-edge, 4) the practicality of content, and 5) the clarity of the proposal. Scores are then tallied and ranked.

8) **A basic package of audiovisual equipment will be available in all session rooms at no charge to presenters this year.** This package includes an overhead projector and an 8x8 screen. If you require additional equipment (such as a slide projector, flipchart or markers, or TV/VCR), you may rent the equipment for the specified cost. Order forms for audiovisual equipment will be sent with acceptance letters. **If a TV/VCR is rented, presenters are required to show tapes that are captioned.**

9) At times letters of acceptance get lost, or go to an incorrect address. **Letters indicating if proposals have been accepted are sent in June.** Do not assume that your proposal has not been accepted if you do not receive a letter. Call the office to check on the status of your proposal. **Letters are sent to the coordinator** to indicate if accepted or not accepted. **It is the responsibility of the session coordinator to notify co-presenters of acceptance.**

10) **If accepted, you may not receive the session time frame or format you requested.** Session assignments are based on the recommendations of reviewers, with final approval by the conference committee. Your session may be accepted as part of an In-focus Strand or as part of a general listing of sessions. The specific session room will be scheduled closer to the date of the conference.

11) **All presenters are required to make the material for their session available in alternate format.** Information on accessible formatting will be provided with letters of acceptance.

The 2000 TASH Call for Presentations is available in alternate format upon request.

2000 TASH Conference Presentation Application

(please be sure a one page abstract is attached to this form)

Date Received:_____

Session Code: _____

COORDINATOR (You may only submit as a session coordinator on **one** proposal) :

_____

Please list below the address which you would like your letters sent in June. This address will be listed in the conference program:

ORGANIZATION : _____

ADDRESS: _____ CITY: _____

STATE/PROVINCE: _____ COUNTRY: _____ ZIP/POSTAL CODE: _____

DAYTIME PHONE: _____ HOME PHONE: _____

FAX: _____ E-MAIL: _____

The above address is: ❒ HOME ❒ WORK ❒ OTHER _____

Session Information

SESSION TITLE *(please try to reflect the contents of the session in the title to assist attendees in choosing a session):*

_____

Requested Session Type:

(Please check only one)

- ❒ 1 HOUR SESSION
- ❒ 2 HOUR & 15 MINUTE SESSION
- ❒ POSTER SESSION
- ❒ TASH TECH (Pre-Conference Workshops)

❒ **I understand that it is my responsibility to contact co-presenters regarding their participation in this session and to inform them of the requirements listed on the guidelines for submission (including payment of conference registration fees) if accepted.**

Signature *(required)* _____

Please type a description of your presentation in 40 words or less. This description will be reprinted in the final Conference Program if accepted. TASH reserves the right to edit descriptions. Please include information on content and format of session.

Applicable Interest Area

(This category determines which committee reviews your proposal. Please pick only one)

- ❒ ADVOCACY
- ❒ AGING
- ❒ ASSISTIVE TECHNOLOGY
- ❒ CREATIVE/PERFORMING ARTS
- ❒ COMMUNICATION
- ❒ COMMUNITY LIVING/HOUSING
- ❒ CRIMINAL JUSTICE
- ❒ INCLUSIVE EDUCATION
  (pick one subcategory)
  - ❒ Urban Education
  - ❒ High School Incusion
  - ❒ International Inclusion
  - ❒ Best Practice
  - ❒ Assessment
  - ❒ Other _____
- ❒ EARLY CHILDHOOD
- ❒ EMPLOYMENT AND CAREERS
- ❒ ETHICS/RIGHTS
- ❒ EUTHANASIA RESISTANCE
- ❒ FAMILY
- ❒ GUARDIANSHIP ALTERNATIVES
- ❒ GOVERNMENTAL AFFAIRS
- ❒ HIGHER EDUCATION
- ❒ LEISURE AND RECREATION
- ❒ MANAGEMENT ISSUES
- ❒ MULTICULTURAL/INTERNATIONAL
- ❒ PARAPROFESSIONAL
- ❒ PERSONNEL PREPARATION
- ❒ POSITIVE APPROACHES
- ❒ RELATED SERVICES
- ❒ RESEARCH
- ❒ SELF-DETERMINATION
- ❒ SPECIAL HEALTH CARE NEEDS
- ❒ SPIRITUALITY
- ❒ SEXUALITY/ SEXUAL EXPRESSION
- ❒ STUDENTS WHO SEVERELY CHALLENGE SCHOOLS BUT WHO DO NOT HAVE "SEVERE" DISABILITIES
- ❒ TRANSITION

Co-Presenter Information

Please remember that it is the responsibility of the Session Chairperson to contact Co-presenters to obtain agreement from them regarding their participation in this session and to inform each Co-presenter of the requirements listed on the guidelines for submission (including payment of conference registration fees) if accepted for presentation at the 2000 TASH Conference.

NAME: _____

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Thank you for your interest in presenting at the 2000 International TASH Conference

Copy this page for additional presenters. Pass a copy of the entire application to a friend or colleague!

2000 Calendar of TASH Chapter and Member-Sponsored Conferences

• • •

May 2000

"Pioneer Spirit - Blazing New Trails" International Parent to Parent Conference 2000
May 5-7, 2000
Reno, Nevada
Host: Nevada University Affiliated Programs
Phone: (775) 784-4921
FAX: (775) 784-4997

• • •

July 2000

First International Conference on Individualized Funding & Self-Determination
July 29 - 31, 2000
Westin Seattle Hotel, Seattle, Washington
For additional information on registration, sponsorship, or scholarships, contact Denise Marshall, TASH, 410-828-8274, ext. 103 or E-mail dmarsh@tash.org

• • •

December 2000 — Annual TASH Conference

Miami, Florida
The Fontainbleau Hilton Resort & Towers
December 6, 2000 - Pre-Conference Workshops & Opening Reception
December 7 - 9, 2000 Annual TASH Conference

• • •

To have your event or conference added to our web site please send information to Denise Marshall at dmarsh@tash.org or fax to 410-828-6706.

PEABODY COLLEGE OF VANDERBILT UNIVERSITY

▼ ▼ ▼

Position Announcements

The Department of Special Education at Peabody College of Vanderbilt University is seeking candidates for Two Open Rank Tenure-track Positions and One Practice Faculty Position in the Area of Early Childhood Special Education (ECSE).

Applicants should have degrees in ECSE, child development, developmental psychology, early childhood education, or closely related fields, excellent teaching records, commitment to collaborative training with early childhood education, and program management expertise.

Further information regarding these ECSE positions can be obtained from Ann Kaiser 615-322-8160 or 615-322-8150; ann.kaiser@vanderbilt.edu)

Review of applications will begin on January 15 and will continue until all positions are filled.

Candidates from underrepresented groups are especially encouraged to apply. Vanderbilt University and Peabody College are committed to promoting diversity in the people and programs that constitute our environment.

▲ ▲ ▲

We've Come Far . . . And Still Have Far To Go

DOUG GUESS

My Early Involvement with TASH

When TASH was started in November, 1974 I was employed as the Director of the Psychology and Research Departments at a residential center for persons with significant disabilities located in Topeka, Kansas. I attended the Bureau of Education for the Handicapped (BEH)-sponsored seminar in Kansas City in 1974, and was a member of the subcommittee that established the American Association for the Education of the Severely/Profoundly Handicapped (AAESPH). I was appointed to the first Board of this new organization. I also introduced the Board members and newly elected officers at the first official meeting of AAESPH in November, 1975.

I have been involved with TASH since its conception in 1974. I served on the Executive Board in all but three years between 1974 and 1988. I have served as secretary (1979/80) and Vice President (1987/88) of the Executive Board. During my involvement with TASH I have been a member of 16 standing or ad hoc committees, and was chairperson for four of these committees. I co-authored two monographs published by TASH. The first monograph (1984) was *Legal, Economic, Psychological, and Moral Considerations on the Practice of Withholding Medical Treatment from Infants with Congenital Defects*. The second monograph (1987) was *Use of aversive procedures with persons who are disabled: An historical review and critical analysis*. Until this year, I have always been a reviewer for the TASH journals, and was the Editor of *JASH* from 1981-1983. I have been a professor of Special Education at the University of Kansas since 1976, and the area Coordinator in our Department for preparing teachers to provide educational services to students with severe and profound disabilities.

How TASH Has Impacted the Lives of People with Disabilities

When I became involved in the establishment of (TASH), most persons with significant disabilities resided in institutional settings where they rarely received minimal educational and vocational training opportunities and, in many cases, were not provided with even basic quality-of-life accommodations. Many of these residential institutions, including one located in Winfield, Kansas, had histories of neglect and abuse toward the residents, not unlike the documented living conditions of persons in Willowbrook Hospital in New York City.

The early TASH meetings were informal, exciting, and stimulating. There existed at these meetings the opportunities to discuss procedures for teaching skills to persons who had been, for decades, perceived as not capable of learning. I was especially involved at these meetings in methods for teaching language and communication skills to individuals who were nonverbal. Presentations often carried over into the evening hours where informal groups assembled to discuss varying approaches to communication training, ranging from Chomsky to Piaget to Skinner. Even the early Board meetings of TASH devoted considerable time, discussion, and debate on issues pertaining to teaching methods and approaches.

TASH's Influence in the Disability Field

TASH has played a major role in helping persuade various states to close institutions, develop community-based services to replace them, and provide educational opportunities in public schools for students with significant disabilities. TASH was most instrumental in the effort to abolish the use of punishers to change behavior, and replace these aversive procedures with the current positive behavior support treatments. TASH has also been a significant change agent and advocate for the infusion of concepts and actions to improve the quality of life for persons with significant disabilities, such as opportunities for expressing choice and self-determination.

Over the years, TASH has brought a great deal of encouragement and support to the families and caregivers of persons who experience severe and profound disabilities. This has been accomplished through the role of TASH as a major advocate for this population of individuals, combined with a direct service

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mission that facilitates both learning and community living opportunities.

Future Directions and Focus of TASH's Work

TASH has been a social change agent for persons who have been underserved and undervalued in our society. The organization has not compromised its values, nor has it shied away from confronting societal policies and practices that are detrimental to individuals who experience significant disabilities and their families. This has included the practices of withholding medical treatment to infants born with disabilities, the use of pain-producing procedures designed to reduce challenging behavior, the resistance to providing educational opportunities in regular schools, and the denial of choice and self-determination in everyday living.

TASH has provided in so many ways the opportunities for persons with significant disabilities to participate, with dignity, in a variety of home, school, and community settings and services. We need, nevertheless, to renew our efforts on the "how." Our instructional capacity and technology for teaching this population of children and adults has, I think, become quite stagnated in comparison to our "civil rights" accomplishments over the past quarter of the century. I would like to see a major effort to involve in TASH a new cadre of scholars and scientists from diverse fields who can "brainstorm" new and innovative procedures, approaches, and outcomes for educating children who experience significant disabilities. I would like to see TASH become once again a forum for exploration, debate, and innovation—a venue for new and creative thinking, and a model for good science based on our established values.

Spirit-Centered Leadership Within Inclusive Schools

COLLEEN A. CAPPER, ASSOCIATE PROFESSOR
EDUCATIONAL ADMINISTRATION, UNIVERSITY OF WISCONSIN-MADISON

MAUREEN W. KEYES, ASSISTANT PROFESSOR
DEPARTMENT OF EXCEPTIONAL EDUCATION, UNIVERSITY OF WISCONSIN-MILWAUKEE

The capacity to develop inclusive school communities into places where all students and staff are valued members is dependent upon administrative leadership and commitment (Keyes, Hanley-Maxwell, & Capper, 1999). We learned about the critical role that administrative leadership played in either making or breaking inclusive school communities (Fox & Ysseldyke, 1997) through an extensive search of current literature (Capper, Theoharis, & Keyes, 1998) and through our own research.

For the past three years, we have conducted studies and taught a course on the topic of spirituality in leadership two times each academic school year (Capper, 1998). We began to probe more deeply into the style of leadership found within administrators staunchly supportive of inclusive communities, and we uncovered core values with spiritual origins as principals revealed their beliefs about inclusion as matters of justice and equity. In the following sections, we offer a brief overview of the six fundamental aspects gleaned from our research findings on inclusive administrative leadership. And we invite readers to help us continue our research by offering your illustrations, questions, challenges, and reflections. Perhaps by expanding our recognition and regard for spirit-centered leadership that supports just and equitable schooling for all, affirmations of respect, value, and human dignity for each will reverberate.

> ***"Educational leaders should be most attuned to their own spirituality. Educators, of all people in our society, ought to be in touch with the best that humans have thought and written about the nobility and sacredness of human life."***

1. Believing in a Divine Power

As opposed to what Parker Palmer (1994) terms "functional atheism [or] the belief that ultimate responsibility for everything rests with me"(p. 35), administrators in our studies acknowledged a divine or cosmic presence in their lives. However, they tended to separate formal religious beliefs from spirituality. One principal explained her definition of spirituality, "I believe it's something within me, my heart, my mind, my soul, it keeps me focused and doing what's good for children." In defining the ways that her spirituality affects her leadership, an administrator said, "[Spirituality] is so much more than morale. I have had people say how important morale is and how we have to make our workplace somewhere people feel good about, but it is more than that—it is an inner spiritualness —it's a personal

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Spirit-Centered Leadership Within Inclusive Schools

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experience, a spiritual side without being religious—it keeps me in balance." Another principal explained, "It comes from within, that's what's happened to me. Believing in a greater power than me, it guides me." Vaill (1990) has described how leaders need to create a unique definition of spirituality of their own, whether natural, supernatural, secular or sacred.

2. Valuing Personal Struggle

Parker Palmer (1994) also described the role depression played in his life, and remembered those who "[stood] at the border of my solitude in that experience because they were not driven by their own fears to either 'fix' or abandon me" (p. 39). The administrators with whom we have worked attributed their capacity to effectively create an inclusive environment for staff and students in large part to their own personal life struggles. For example, one principal described his experience with a brother with disabilities who was scapegoated throughout school, did not have friends, and ended up in prison after high school. Another administrator named several critical incidences on his spiritual journey. While recounting his father's near death experience, he explained, "As a farm kid who grew up in central Illinois, I had the pleasure of working side-by-side with my father for eighteen years. He was an incredible man; a soft, sensitive giant. It was through these conversations with my father and brothers in the buttonweed patches in the soybean fields where it was 95 degrees that I learned to be sensitive to others, to help thy neighbor, to put in an honest days work regardless of the pay, and love and value nature and land." Another administrator agreed, "I know what it's like. I know a lot of things that people go through. My job is to accept people where they are and hope that by what I say and what I do that together we look at things in a different way so that maybe they won't need to have anger or hostility to explain life to themselves." The personal struggles of these spirit-centered leaders enhanced their understanding of others' perspectives.

3. Possessing a Sense of Divine Mission Oriented Toward Equity

Bolman and Deal (1995) in their popular book, *Leading with Soul*, advocated for a leadership that "returns us to ancient spiritual basics—reclaiming the enduring human capacity that gives our lives passion and purpose" (p. 6). The administrators spoke about the sense of divine mission they felt in their equity work. These leaders believed they must be good stewards of their own gifts and sought to create the conditions for the gifts of others to come to fruition. One administrator explained, "The older I get, the more important it is for me to make a difference . . . . because when it's all said and done, isn't that what our existence is about, making a difference and leaving the world a little better place than when we entered it?" A high school principal agreed, "I am really feeling that I have a purpose, there's a divine power that kind of guides me. My purpose in life is to support children and help them so they can be productive citizens and figure out ways to support my staff to help children learn and grow. That is my purpose, that is why God, the divine power, has put me here, brought me this far." For these administrators, not only did they feel guided by a mission in their work, but this mission was inspired and directed toward helping alleviate the struggles of others.

4. Advocating for Persons Who Struggle

Shaped in part by their own experiences of pain, these principals were especially sensitive to those who struggled in schools. For example, one principal shared about the suicide attempts of her sister and how this influenced her leadership. She noted, "I'm deeply affected when I see another human being hurt. I just can't stand it." Another administrator described how one teacher severely criticized a teaching candidate at his school: "[The teacher] said, 'I couldn't live with that person.' She said the candidate was someone whose life she couldn't value." I said to her, 'we can't judge one person's life as being more valuable or not, because she is a person and deserves respect for who she is, not judged by what her life could mean to another teacher.'" All these administrators emphasized the importance of belonging in their schools not only with students, but with staff as well.

5. Believing People are Inherently Good Combined with a Bottom-Line

These school leaders all believed that staff and students were doing their best. As one administrator explained, "I believe that people are inherently good and that poverty, ignorance, abuse, adversely affect people in ways that are beyond their control." A second principal echoed, "I do believe that people want to do the right thing. It's not that people are bad, it's sort of their competitiveness, that if I give this up, I lose something." The principals noted that people who seemed angry or aggressive were probably in pain, and perhaps unable to express their unhappiness in other ways.

Although the principals recognized that others were moving along their own life paths, they believed that part of their responsibility was to encourage individuals to consider other perspectives. One elementary principal explained, "One of the things I believe is so important is that staff members have to know who you are and what the non-negotiables are . . . when their belief system does not match what we say are non-negotiable, we give them as much support as we can . . . but let them have an out." These principals practiced spiritually-centered leadership within the context and goal of empowering all students. Not all ideas were open to critique, for example, whether students were protected from harassment from other students, or whether students with disabilities would be included as much as possible within the general education classroom. The administrators were clear about their "bottom-line" goals, however, they encouraged and supported teachers to explore their own ways to reach the goals.

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Spirit-Centered Leadership Within Inclusive Schools

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6. Gathering Spiritual Support to Realize the Equity Dreams

The principals acknowledged that advocating for students who struggled in school sometimes met with resistance. Therefore, they cited the importance of creating spiritual support for themselves to carry out their equity work. One principal described how she and two other African American principals created "... a support group that has grown to a membership of eleven other African American [principals] ... a group of very spiritual women." They gather once a month to brainstorm ideas in response to struggles, and to support new principals in navigating through the political system. Another high school principal described the importance of support in the midst of challenges: "The more leadership you assume, the antagonistic forces can attack you more and more and you may start being called the exact opposite of what it is you are trying to do ... people will say you don't care about kids. I think you have to have a best friend in the sense of spirituality or you self destruct." These spirit-centered administrators realized that equity work can be difficult, and that they could not do it alone. They developed relationships with like-minded people for ongoing spiritual support.

As Starratt and Guare (1995) invite, "Educational leaders should be most attuned to their own spirituality. Educators, of all people in our society, ought to be in touch with the best that humans have thought and written about the nobility and sacredness of human life" (p. 196). We are not saying that all principals who are working toward equity in their schools share a similar spirituality, or that all principals who engage in spiritual practices make equity their priority. These six dimensions of a spiritually-centered leadership, however, illustrate how the spiritual beliefs of innovative educational leaders intertwine with their inclusive practices, embracing the challenges of diversity.

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Spirit-centered Leadership 1

The Creation of TASH

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TASH NEWSLETTER

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement.

Priscilla Newsum, *Editor*

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Funds must be submitted in U.S. dollars and checks must be drawn on a U.S. bank. Add a $20 processing fee if check is not drawn on a U.S. bank. If you would like to change your membership, please fill in the necessary information in the next column.

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